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Full Name of Author — Nom complet de l'auteur
GRAEME THOMAS CLARK

Date of Birth — Date de naissance
16 NOV 51

Country of Birth — Lieu de naissance
CANADA

Permanent Address — Résidence fixe
#407 - 8210-111 St.
Edmonton, ALTA
T6G 2C7

Title of Thesis — Titre de la thèse
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Name of Supervisor — Nom du directeur de thèse
Dr. Allen Vander Well

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PATTERNS OF FAMILY INTERACTION IN THE CONTEXT OF CHRONIC ILLNESS

BY

Ⓒ GRAEME T. CLARK

A THESIS
SUBMITTED TO
THE FACULTY OF GRADUATE STUDIES AND RESEARCH

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IN
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#407 - 8210 - 111 Street
Edmonton, Alberta
T6G 2C7

DATED . . 8 OCTOBER . . . 1981

THE UNIVERSITY OF ALBERTA

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "Patterns of Family Interaction in the Context of Chronic Illness", submitted by Graeme T. Clark in partial fulfilment of the requirements for the degree of Master of Education in Counselling Psychology.

Allen Vanderwell
Supervisor

D. D. Sawatzky

J.W. Vargo

Date 8 OCT 1981

TO STEVE TAYLOR

who exemplified humor, straightforwardness
and courage through his living and his dying

ABSTRACT

Within the context of a chronic illness, cystic fibrosis, this research addressed two inter-related aims. First, each of three family systems was considered with respect to patterns of information feedback maintaining the family as a stable unit and promoting family accommodation to individual developmental changes. Individual changes were examined with particular reference to the independence of the identified patient. Second, the systems interactional framework which guided the collection and analysis of data was evaluated with regard to its efficacy as a system of research. The first objective was accomplished by means of a discovery-oriented research process, which involved the collection of interactional data from the three families via a semi-structured interview, and the subsequent analysis of this data according to the systems interactional perspective. The second objective was accomplished by means of exploring the entire research process in terms of the writer's experience as participant observer.

Analysis of the interview data revealed the patterned and rule-governed ways in which each family system regulated stability and change. All three

families had enjoyed considerable success in adapting to the challenge of chronic illness, and certain families demonstrated interesting qualitative differences in their functioning as mutually interdependent units. These differences were related to the flexibility and openness of family interactional process.

While the system of research was undoubtedly limited by a number of factors, the overall approach seemed particularily applicable to the study of complex interactional systems. It facilitated the exploration of several unexpected findings, suggested a variety of family counselling interventions, and indicated fruitful areas for further research. In addition, as an approach which explicitly considers the investigator's involvement in the research proceedings, the interactional systems framework was highly commended. In the writer's view, the research process of this thesis initiated a fascinating, exciting and rewarding growth experience.

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CHAPTER I

INTRODUCTION

The problems of everyday living experienced by teenagers and young adults affected with cystic fibrosis (see Appendix A) have received increasing attention as recent advances in diagnosis and medical management have lengthened the expected lifespan (Frydman, 1979; MacLeod, Houghton & MacLeod, 1980). Living successfully with a chronic medical condition like cystic fibrosis presents a very difficult challenge to patient and family alike. It is the writer's observation from working with such patients that while some individuals readily succumb to their illness, withdrawing from the active world to spend greater amounts of time either at home or in hospital, others get on with the business of living, pursue their education, acquire job skills, and lead generally active, satisfying lives despite the inevitable deterioration and death they must encounter. One aspect of the foregoing observation, namely, how it is that certain patients live so successfully in the face of such adversity, provided the focus of this thesis.

The research encompassed two inter-related aims. First, each family system was considered with respect to patterns of information feedback maintaining the family as a stable unit and promoting family accommodation to individual developmental changes. Individual changes were examined with particular reference to the independence of the identified patient. Second, the systems interactional framework which guided the collection and analysis of data was evaluated with regard to its efficacy as a system of research. The first objective was accomplished by means of a discovery-oriented research process, which involved the collection of interactional data from three families via a semi-structured interview, and the subsequent analysis of this data according to the systems interactional perspective (Watzlawick, Beavin & Jackson, 1967). The second objective was accomplished by means of exploring the entire research process in terms of the writer's experience as participant observer (Becker, 1958).

This research entailed a new way of looking at an old problem. In the past, adaptation to chronic medical conditions has been studied from numerous viewpoints. For example, original work in sociology emphasized the importance of the sick role, and the family affected by sickness was viewed in terms of disrupted role-allocation (English, 1977; Parsons,1979).

Social learning theory, a later derivative of the social role perspective, incorporated role ideas with learning theory to form the basis of an approach to rehabilitation counselling (Roessler & Bolton, 1978; Wooley, Blackwell & Winget, 1978). From within the field of rehabilitation, research relating adjustment to traditional psychological variables such as personality has revealed that individual adaptation to disability is highly variable. Descriptive studies concerning psychosocial adaptation to cystic fibrosis, as exemplified by Falkman (1977), Goldberg, Isralsky and Shwachman (1979), and Tavormina, Kastner, Slater and Watt (1976), have shown similar patterns of individual variability.

With the exception of the social learning perspective, past efforts have generally failed to connect research methods and results with counselling practice. The same criticism can be made of more family-oriented research. As the vital influence of the family has been increasingly recognized, the mutual relationship between the family unit and the individual affected by disability or chronic illness has been described from a variety of standpoints (Litman, 1974; Sumpter, 1980). With specific reference to cystic fibrosis, numerous studies have documented the successes and difficulties experienced by patients and their families (Boyle, di Sant'Agnese, Sack, Millican & Kulczycki, 1976; MacLeod et al., 1980; Rosenlund & Lustig, 1973). While these studies have underlined the need for adequate family counselling services, they have done little to suggest appropriate counselling interventions, and have in fact highlighted the need for a methodology from which to conduct family investigations.

The writer is in agreement with Frydman (1979), who noted that additional research is required "that attempts to do more than merely catalogue the general areas in which problems are reported" (p.148). With respect to both cystic fibrosis and other chronic medical conditions there is an overall lack of research that has been conducted from within conceptual frameworks explicitly connected to counselling approaches.

By considering the problem of adaptation to cystic fibrosis in terms of relational variables as opposed to traditional internal variables (e.g. self-concept), the writer identified patterns of family interaction associated with relatively functional, independent adaptation on the part of the identified patient. Once such patterns were recognized, it was possible to suggest family-oriented interventions which could be used to assist other families in developing more functional and more fulfilling adaptive behaviors. In this regard, Haley (1978) has written:

> Thinking in terms of systems, one can plan a therapy in which a crisis is induced, thereby forcing the whole system to reorganize. Or one can start a small change and persistently push it until the change is so amplified that the system must change in order to adapt to it. The chief merit of the systems theory is that it allows the therapist to recognize repeating sequences and so make predictions. He can then plan his therapy in anticipation of what will happen. The problem is how to simplify the sequences so they become recognizable and, therefore useful. (p.77)

In summary, the present research addressed the general problem of determining how the family of the cystic fibrotic individual had accommodated itself to the difficult situation of having one or more members thus affected. It also explored the value of the systems interactional frame of reference as a systematic approach to inquiries of this nature. The following research questions were investigated:

1. What feedback patterns have promoted stability in the family interactional system?
2. What feedback patterns have promoted change in the family interactional system?

3. On the basis of feedback patterns, what rules can be inferred about the family's interactional system?
4. What are the limitations and advantages of the interactional perspective as a system of research?

CHAPTER II

RELATED RESEARCH AND LITERATURE

The following review of related research and literature is presented in three major sections: (a) an examination of perspectives from which adaptation to chronic illness and disability has been studied, (b) an exploration of specific psychosocial findings regarding adaptation to cystic fibrosis, and (c) an elucidation of systems thinking in family theory, therapy and research. The latter section provides the methodological and analytical framework for the present research, and concludes with a summary of relevant findings emerging from the literature review.

Perspectives on Chronic Illness and Disability

Contributions to the understanding of adaptation in the face of chronic illness and disability have emerged from numerous disciplines, and this section briefly mentions some of the more influential perspectives. Consideration is given to social role theory, social learning theory, trait and factor perspectives, and finally, various approaches to the family.

Social Role Theory

Social role theory, initially presented by Parsons in 1951, has remained widely influential in the fields of sociology, psychology, and rehabilitation. Parsons conceived of illness behavior as encompassing both psychodynamic disturbance and a deviant social role, but focussed upon the capacity for effective role performance as the primary factor discriminating health from illness (English, 1977; Parsons, 1979; Parsons and Fox, 1978). Role was defined as the "organized system of participation of an individual in a social system, with special reference to the organization of that social system as a collectivity" (Parsons,1979, p.122), and the sick role was described specifically in terms of four features: (a) the ill person is not held responsible for the resulting incapacitation; (b) the ill person is granted exemption from normal roles and responsibilities; (c) the sickness is socially legitimized insofar as the person tries to re-attain health by co-operating with others; and (d) the ill person is expected to seek competent help.

According to Parsons,the sick role is deviant in the sense of allowing a passive withdrawal from normal functions and responsibilities, but providing the role is played in accordance with societal expectations, it remains socially condoned. Since the associated expectations are learned, the particular way in which an individual enacts the role will vary depending upon factors such as learning ability, personality traits, and previous role model exposure (English, 1977). In addition, the sick role is learned in correspondence with a reciprocal care-giving role played by one or more other people.

Extensions of social role theory into rehabilitation practice are partially based on the recognition that the illness of one family member disrupts the traditional allocation of roles in the family system and necessitates role reorganization. Research has added credence to this notion (Anthony, 1970; Bishop & Epstein, 1980; English, 1977; Wawzonek, 1974). For example, in an extensive sociological study of health and the family, Litman (1974) found that illness generally affected normal role performance and led to role disequilibrium in the family. Both cross-sectional and longitudinal data were obtained in this research, through a series of interviews with the members of 201 nuclear families. In cases of chronic or more complex illness, a higher instance of role accentuation and alteration was reported, and such effects seemed to vary with family size: families containing two to four members were more prone to experiencing dramatic role changes, while larger families were more likely to demonstrate adaptability.

Another hypothesis originating with social role theory, that degree of disability will correspond to degree of role disruption, has not been supported by research (Bishop & Epstein, 1980; Sumpter, 1980). Bishop and Epstein suggest that findings are explained more accurately by a curvilinear relationship. Accordingly, mild disability heightens role disruption because of confused expectations, and severe disability, where the disabled person's role capacities are clearly defined but low, leads to role overload for others. In the case of intermediate disability, clear role allocation according to capacity is possible, other family members are not overburdened, and the disabled individual presumably gains status and self-esteem through effective role functioning.

Although it is generally accepted that the sick role perspective does not adequately explain many aspects of illness and disability (Kutner, 1971), it has been valuable to rehabilitation counselling because it provides the therapeutic rationale behind restoring or maximizing role performance of the disabled individual. The importance of effective role modelling, flexible role allocation, and normal role maintenance inasmuch as is possible, has been widely recognized (Buscaglia, 1975; Khan, 1979; Kutner, 1971; Mailick, 1979), and both the social learning and family systems perspectives have benefitted.

The Social Learning Perspective

Recent models outlined by Roessler and Bolton (1978) and Wooley, Blackwell and Winget (1978) are built around the learning aspects of the social role perspective, and consider both person variables and environment variables in designing a treatment program. Over a period of four years, Wooley et al. treated 300 hospitalized patients suffering from headaches, seizures, uncontrolled diabetes, asthma, and the like, from the viewpoint that illness behavior is a learned social role, shaped and maintained by social contingencies in the patient's environment. Common sick role behaviors exhibited by these patients were examined in terms of the reciprocal responses they elicited in others. For example, displays of helplessness tended to elicit either support or advice, whereas threatening behaviors resulted in either ameliorative or controlling responses. Such patterns of reciprocal behavior simultaneously legitimized the sick role while maximizing personal gains for the patient (and for the helper?). At a one-year follow-up, a tailored treatment program yielded 26 partial or total successes in a group of 36 patients. This program incorporated learning principles to eliminate inappropriate social reinforcers while eliciting and reinforcing independent behaviors. Interestingly, the significant factor in predicting success, defined in terms of cessation of complaints and ratings of achievement, was whether or not the patient returned to an intact family.

Disability, Chronic Illness and Rehabilitation Psychology

Within the realm of rehabilitation psychology, adaptation to a wide range of disabilities and illnesses has been researched with reference to many traditional psychological variables. Briefly, these have included the following:

Personality. The hypothesis that specific disabilities and illnesses correlate with specific personality patterns has spawned extensive research. Roessler and Bolton (1978) and Shontz (1977), among others, concluded in their research reviews that the hypothesis is not generally supported. For example, Roessler and Bolton analyzed 19 studies of the physically and psychiatrically disabled in which

Cattell's Sixteen Personality Factor Questionnaire (16PF) had been used. The three most significant personality correlates to emerge were emotionally less stable, apprehensive, and tense, which are all aspects of the broader personality dimension of Anxiety. This analysis was limited by differences in designs, norms, forms of the 16PF, and samples, as used across the 19 studies, and the authors noted that as much variation was found within disability groups as within the general population.

Psychological maladjustment. A second hypothesis in the rehabilitation field, that severity of disability correlates with degree of psychological maladjustment, has also been researched extensively. Again, both Roessler and Bolton (1978) and Shontz (1977) conclude that the hypothesis is not generally supported, although it seems clear that the relationship between these variables is complex. For instance, Pless, Roghmann, and Haggerty (1972), in a study comparing 209 chronically ill children, aged over six years, with 190 healthy children, estimated on the basis of parent, teacher, and self-report ratings that the chronically ill group showed a 10-15% higher frequency of psychological maladjustment. Additional analysis revealed a telling factor: those children highest at risk were rated lowest on family functioning.

Both Roessler and Bolton (1978) and Shontz (1977) cite research findings which suggest that individuals with a disability or illness do show increased depression and somatic concern. However, even these findings remain to be clarified, since such studies can often be criticized for having failed to control the time dimension. Shontz (1977) notes that change in health status, for worse or for better, seems to promote temporary disorganization, and may be more relevant to general adjustment than illness or health per se. Thus, in this type of research, which typically relies upon amalgamated group data, the specific time of testing may be a crucial variable.

Other personal adjustment variables. A wide variety of other personal adjustment variables have been researched, often in relation to rehabilitation outcome, but are mentioned here only in passing. These include vocational measures, motivation, self-concept and related measures, perceptual variables, organismic factors, expectancies, environmental dimensions, cultural influences, and the nature of the illness or disability (Kutner, 1971; Lipowski, 1970; Roessler & Bolton, 1978; Shontz, 1977).

Disability, Chronic Illness and the Family

The central importance of the family in promoting functional adaptation to disability and chronic illness is widely recognized. For example, Buscaglia (1975) writes the following:

> No matter how many professionals will work with the person who is disabled during his lifetime, there will be none who will have a more poignant, influential, lasting and significant effect upon him than that of his family. The family members will be in constant contact with him. They will teach him the mores and folkways of the culture and they will stipulate the rules for the game of life. They will, in a very real sense, guide him in his struggle to be human. Their attitudes toward him as a person will have great authority over the attitudes he will have about himself. Their feelings about his impairment will affect his feelings toward it. For better or for worse, his first and most influential counsellor will always be his family. (p.119)

Although there is a paucity of studies which are not just anecdotal, the available research does strongly suggest that aspects of family attitude and behavior do exert significant influences upon individual adaptation, one way or another. In the previously mentioned studies by Wooley et al. (1978) and Pless et al. (1972), family intactness and family functioning were the dimensions which discriminated treatment success from failure, and high risk of psychological maladjustment from low risk, respectively. In rehabilitation settings, supportive families have been linked with increased vocational success (Lindenberg, 1979), and Litman (1974) cites studies which show, first, that health care attitudes and practices are learned primarily in the family setting from one's parents, second, that compliance to physicians' orders increases in those families which expect compliance, and third, in the presence of a supportive family constellation rehabilitation response is more satisfactory.

Dysfunctional adaptation is reportedly promoted in those families which orient family life entirely around the caring function (Steinhauer, Mushin, & Rae-Grant, 1974; Wawzonek, 1974). In a study of blind children cited by Lindenberg (1979), slow overall development was associated with heightened parental protectiveness. Along the same line, Felice and Friedman (1980) assert that a major problem facing the chronically ill child is that of attaining age-appropriate independence. Not only parents tend to overprotect, as physicians often promote unnecessary restrictions, other health care staff fail to provide realistic career guidance, and adult patients continue to attend pediatric specialists.

In the writer's view, the overprotective dimension seems to be related to the finding that serious illness challenges family cohesion and can result in very positive or very negative effects (Litman, 1974; Sumpter, 1980). For example, Litman's research with 201 nuclear families revealed that illnesses which were perceived as more severe stood a significantly greater chance of affecting family cohesion, with 50% of such families coming closer together and 50% moving further apart. The influences underlying these trends were not clear, but it seems reasonable to suggest that the following scenario could account for such divergent family developments: (a) The difficulties faced by families of the disabled and chronically ill involve "exaggerations and variations of the complex developmental struggles of all children and families" (Sumpter, 1980, p.175). (b) In the family with tenuous marital adjustment, father retreats from family involvements as his wife becomes increasingly involved with "forming an unnatural, mutually dependent role with her disabled child ... so that ... her meaning as a woman and mother can now only be fulfilled through the child's continual dependence" (Buscaglia, 1975, p.123). (c) The parents are divided between themselves, and the child takes on power by virtue of helplessness, and disrupts the usual hierarchy of authority in the family (Haley, 1980, p.82).

The foregoing scenario illustrates that the family affects adaptation to chronic illness and disability, and is in turn affected by the ill or disabled person. It is generally accepted that disability and chronic illness exert significant influences upon the family. Sumpter (1980) mentions social isolation, chronic sorrow, and sibling resentment; Pless (1980) lists emotional exhaustion, embarrassing social reactions, restricted social relations, adverse sibling responses, and innumerable practical hardships; while Khan (1979) and Steinhauer et al. (1974) detail adverse emotional reactions associated with guilt, shame, anxiety and fear. Steinhauer et al. also stress that family reactions may be mediated by factors such as prognosis, nature of disease transmission, age of patient at onset and diagnosis, presence of other affected siblings, repeated hospitalizations, and financial costs.

Unfortunately, the general documentation of such effects, relating disability and chronic illness to the family from one angle or another, has done little to advance the understanding of functional and dysfunctional adaptation. It can be seen that while the discovery of the family by rehabilitation and health care workers has stimulated numerous anecdotal reports and some research, it has at the same time inevitably pointed to the lack of appropriate methodologies and perspectives through which to further the understanding of family and health complexities. Commenting on this problem, Bishop and Epstein (1980) suggest that a systems-oriented approach might be most appropriate. A few applications of this approach in the health care field have been reported, and these are reviewed below.

A pioneering study by Titchener, Riskin and Emerson (1960), attempted to show that adaptation in a case of ulcerative colitis was "conditioned by an interlocking set of relationships within the family" (p.142). The mother of the family in question demonstrated an overly close relationship to her son, who in turn experienced a harsh and distant relationship with his father. It was observed that when the mother distanced herself from her son, the father tended to overwork and demanded similar behavior on the part of his son. With the onset of ulcerative colitis, the son was able to legitimately withdraw from the father's expectations, and in the process regained a closer relationship with his mother. Titchener et al. described this family in terms of unbalanced coalitions involving the son, and conflict in the marital relationship.

Other research has been done with families of cerebral palsied children and of paraplegics. Schaffer (cited in Dell. 1980),found that cerebral palsied children from families that were excessively cohesive showed more helplessness, emotional dependence and egocentrism than did children from less cohesive families. This finding seems to fit with the work of Cogswell (1976) in relation to a group composed predominantly of paraplegics and their families. Accommodation to paraplegia was enhanced by role flexibility and by permeable entry/exit boundaries. One family which demonstrated impermeable boundaries, or excessive cohesion, was less able to accommodate the changed situation brought about by paraplegia.

Additional studies have involved families of epileptic children (Ritchie, 1981), cancer patients (Cohen & Wellisch, 1978), kidney disease patients (Stewart & Johansen, 1976/77), and asthmatics (Liebman, Minuchin & Baker, 1974). The latter research is of particular interest because it illustrated the manner in which a variety of interventions follows naturally from a family systems assessment. Each of the seven families in this study presented a child exhibiting intractable asthma, and patterns of parental overprotectiveness and avoidance of conflict resolution were typically observed. As in the case of ulcerative colitis described earlier, the mothers were usually overinvolved with their asthmatic children, while the fathers were more peripherally involved. Treatment was directed toward disengaging the identified patient from marital conflict, thereby enabling the child to participate in appropriate sibling and extra-familial activites. This goal was accomplished via a number of interventions at different points in the system, such as: (a) increasing father-child involvement by having them practise breathing exercises together, (b) increasing mother-father involvement by instructing them to work together in treating asthma attacks at home, and (c) increasing both mother-father contact and child-sibling contact by confronting parents about the preferential treatment enjoyed by the identified patient and encouraging them to facilitate more age-appropriate peer and sibling activities.

Psychosocial Adaptation to Cystic Fibrosis

Most previous studies in the area of psychosocial adaptation to cystic fibrosis have presented descriptive group data from outpatient clinic populations, in the absence of control group comparisons and without detailed breakdown with regard to age, sex or socioeconomic status, much less with regard to functional level of adjustment. A major criticism of such studies is that although they frequently conclude by emphasizing the need for counselling in the cystic fibrosis situation, they have themselves been conducted in a methodological and theoretical manner which fails to suggest counselling interventions.

Apart from the foregoing criticism, the interpretation of past research is complicated by the recognition of cultural and technological influences. Some studies have originated outside of North America, in countries such as Sweden (Falkman, 1977), and Australia (Allan, Townley & Phelan, 1974), but authors have failed to acknowledge possible cultural variations. As well, the effects of change within a culture, such as those related to improved financial assistance and to the evolution of non-traditional role allocations in the family, are difficult to account for. Technologically, the diagnosis and treatment of cystic fibrosis has changed dramatically (see Appendix A) so that families now face a very different prognostic picture than did earlier families. This fact may account for extremely negative findings such as those of Lawler, Nakielny, and Wright in 1966.

In the following section, research concerning psychosocial adaptation to cystic fibrosis is reviewed with special attention to the teen and young adult age group. Findings with regard to individual adjustment of patients, parents and siblings, from within a framework of traditional psychological variables, are briefly described. Since clinical researchers have typically considered global adaptation in terms of isolated variables, rather unsystematically from one study to another, patterns of family interaction have not been well-elucidated. However, some trends regarding functional and dysfunctional parental role allocation and communication are revealed, and these are discussed in detail.

Intellectual, Academic and Vocational Development

Overall, the available research suggests that cystic fibrotic individuals function in the average or above average range of intelligence. Boyle et al. (1976) administered either the Wechsler Adult Intelligence Scale or the Wisconsin Intelligence Scale for Children to a mixed sample of 27 patients aged from 13 to 30 years, and determined an I.Q. range of 82 to 150, with a mean of 113 and a standard deviation of 14.6. Additional data given by Cytryn, Moore and Robinson (1973), Falkman (1977), Lawler et al.

(1966), and Spock and Stedman (1966) generally support these findings.

The contributions of academic and vocational activities to self-identity formation and to general quality of adaptation have been widely recognized (Goldberg, Shwachman, & Isralsky, 1980; Lewiston, 1980; Wood, 1979). Early survey data about a group of 11 patients suggested the prevalence of academic under-achievement (Lawler et al., 1966), but more recent surveys by Boyle et al. (1976) and Swachman (1977) show consistently high levels of academic and vocational achievement among adolescent and young adult patients. Boyle et al. also considered academic and vocational success against clinical ratings of disease severity, and concluded there was no significant correspondence.

It was determined by Goldberg, Isralsky and Shwachman (1979), in a study comparing 25 randomly selected patients ranging in age from 12 to 18 years to a matched sample of public school students, that cystic fibrotic teenagers generally showed lower specificity of vocational and educational plans and lower degrees of realism in their planning, but higher levels of vocational commitment and occupational awareness. These conclusions were drawn on the basis of independent ratings of replies to a semi-structured questionnaire schedule, the Goldberg Scale of Vocational Development. This instrument was used in a second study by Isralsky, Goldberg and Shwachman (1979) to test 52 cystic fibrotic subjects having a mean age of 19.3 years. The Goldberg Scale of Vocational Development revealed no significant correlations with clinical ratings of disease severity, and no significant correlations with self-concept scores yielded by the Tennessee Self Concept Scale.

Emotional Functioning and Personality

Several impressionistic or uncontrolled clinical studies report a generally high incidence of feelings of anxiety, depression, inadequacy, and insecurity among cystic fibrotic individuals (Boyle et al., 1976; Lawler et al., 1966; Tropauer, Franz, & Dilgard, 1970). However, suggestions that such patients demonstrate unusual disturbances of personality have not been supported by more exacting research. In an extensive study by Tavormina et al. (1976), a battery of personality functioning tests was administered to a group of 144 asthmatic, cystic fibrotic, diabetic and hearing-impaired children with a collective mean age of about 12 years. Testing included the Piers-Harris Self-Concept Scale, the

Junior Eysenck Personality Inventory, and the Missouri Children's Picture Series, and results were compared across groups and to appropriate age and sex norms. Profiles of the asthmatic, diabetic and cystic fibrotic groups were all close to scale norms. Additional support for the conclusion that cystic fibrotic individuals show an average range of personality functioning derives from Gayton, Friedman, Tavormina, and Tucker (1977). These investigators tested 43 patients with the Piers-Harris Self-Concept Scale, the Missouri Children's Picture Series, and the Holtzman Inkblot Test. Results for the 5 to 13-year age group were again within average ranges, and data for the 14 to 18-year age group, which were not treated statistically due to small sample size, appeared consistent.

With respect to the emotional and personality adjustment of other family members, depression and periodic dejection is often reported among mothers of cystic fibrotic individuals (Allan et al., 1974; Lawler et al. 1966; McCrae, 1975; McCrae, Cull, Burton, & Dodge, 1973; Tropauer et al., 1970). The fathers of cystic fibrosis patients are generally neglected in reports of psychosocial research, although Gayton et al. (1977) did administer the

Minnesota Multiphasic Personality Inventory to the available fathers in their sample of families, and found a significantly high proportion of elevated profiles in comparison to fathers of normal pre-adolescent boys. Probably the most telling statement about paternal involvement in health care derives from the consistent demonstration that either the medical and research establishment has failed to include fathers in research or the fathers have for some reason failed to include themselves. Among physically unaffected siblings, high rates of attention-seeking and other behavior disorders are reported (Allan et al., 1974; Rosenstein, 1970). Again, however, in terms of more standardized personality measures, Gayton et al. (1977) found no significant differences between affected and unaffected siblings, and all scores were within average scale ranges.

The Family and Cystic Fibrosis

The diversity of family response in the context of cystic fibrosis has been widely documented through a number of impressionistic, uncontrolled studies. Strained marital relations, decreased family satisfaction and adjustment, adverse sibling behavior, altered mobility patterns and restricted extrafamilial involvement have all been reported (Denning, Gluckson & Mohr, 1976; Gayton et al., 1977; Lawler et al., 1966; Mayerowitz & Kaplan, 1967; Turk, 1964). As well, the four adaptive phases experienced by each family have been identified as prediagnosis, confrontational, long-term, and terminal (McCollum & Gibson, 1970). During the long-term adaptational phase the family must maintain a relationship with a potentially dying individual, and may fluctuate between periods of mourning and denial.

In accordance with the findings of Litman (1974) cited in the previous section, there is little doubt that the presence of cystic fibrotic offspring affects the marital relationship. For example, Rosenstein (1970) reported that 11 of 62 families had endured divorce or separation and that many others showed fragile relationships. McCrae et al. (1973) reported that 16 of 100 married couples had divorced, separated, or suffered severely restricted relationships, but also asserted that many families had been strengthened by the challenge of cystic fibrosis. Sibinga, Friedman and Huang (1973) noted that the illness inevitably interacts with ongoing family patterns and may provide certain inadequate parents with a common purpose. In a somewhat more exacting study, Begleiter, Burry and Harris (1976) interviewed 31 cystic families and administered a brief questionnaire to assess marital effects. Results showed that 22 couples perceived cystic fibrosis as a uniting force in their marriage, and the divorce rate obtained was no higher than that for the general population.

An interesting study by Kerner, Harvey and Lewiston (1979) provides another picture of the intense family involvement around cystic fibrosis. These authors conducted a retrospective interview study of 16 families who had lost a child to cystic fibrosis an average of 2.5 years previously. The average age of the person who had died was 15 years, with a range of 6 to 24 years. A variety of parental and sibling reactions were reported, including psychiatric difficulties, chronic mood changes, and stress-related illnesses, but most notable was the finding that 7 out of 16 families maintained the deceased's room as a shrine, or visited the grave weekly, or both. Of the 6 families who kept the room as a shrine, five were beyond the one-year anniversary of the death. Kerner et al. concluded that while cystic fibrosis families are prepared for death by the extended disease course, they experience marked difficulty in completing the mourning process. Unfortunately, these investigators did not discover any dimensions which differentiated incomplete from complete mourning families.

A number of studies are suggestive of family communication patterns and constellations of family organization which are associated with functional or dysfunctional adaptation. The early study by Meyerowitz and Kaplan (1967) examined family response to the stress of cystic fibrosis by means of a questionnaire and interview method. While limited by the fact that only 13% of the 157 cystic fibrotic individuals were aged 10 years and over, interesting trends in family interaction were indicated. The degree of psychophysiological stress experienced by parents was significantly related to both the child's information-seeking behavior about prognosis and the child's involvement in outside activities, while the prior death of a child from cystic fibrosis corresponded to parental overrating of disease seriousness and heightened protectiveness in relation to surviving cystic fibrotic offspring. These findings suggested that open parental discussion of the situation might be avoided or curtailed in order to alleviate emotional distress, and that the protective role might be heightened in order to gain a similar emotional payoff.

Lewiston (1980) noted that bonding and self-identity issues are a primary concern for adolescent and adult patients. These individuals must unbond from their parents in the process of establishing a separate identity, and form bonds with others outside the family. Such developments are hindered not only by aspects of cystic fibrosis itself (for example, the intermittent cough), but also by the classical overprotective mother/withdrawn father constellation. The general difficulties of this situation in the case of cystic fibrosis are widely recognized (Fischman, 1979; Hilman, 1973; McCrae, 1975; Rosenlund & Lustig, 1973; Turk, 1964; Winder & Medalie, 1973), although the prevalence of the particular type of family organization is not documented, and its actual influence is little understood.

Commenting on this particular problem, Falkman (1977) wrote:

> The physical nearness between mother and child involved in therapy and treatment for all groups of children is often perceived as positive when the child is young, but later on turns into something negative as the older child strives for independence. The close involvement often leads to overprotection from the mother and a very close mother-child unit is often found, sometimes expelling the father to the position of an outsider. The same situation has been found in families with asthmatic children, hemophilic children and in families where a child suffers from Tay-Sachs disease [references removed]. (p.10)

As one aspect of her study, Falkman interviewed the mothers of 50 randomly selected families who had a total of 52 cystic fibrotic children ranging in age from 4 to 15 years. When asked about the quality of their marital relationship, 19 mothers indicated it had improved because the illness united the couple and overshadowed other problems they might have experienced; 17 mothers reported no change in the quality of their marriage; and 13 mothers indicated the illness situation had weakened their marriage because of demands on the mother and a lack of assistance from the father. The 36 women reporting positive or neutral effects on marital quality seemed to share mutual support and relatively open communication with their spouse. The 14 other women (including one widow) reported that mutual communication had been extremely difficult. One woman had explicitly protected her husband from the details of cystic fibrosis, and nine others had wanted to discuss concerns but did not because of their husband's disinterest, in four cases, and extreme sensitivity, in five cases.

Tropauer et al. (1970) asserted that the probability of problems within a cystic fibrosis family increased as communicative openness and emotional support decreased. This conclusion was based upon their somewhat anecdotal interview study of 23 mothers and 20 affected children, and seemed to be supported by the later findings of Boyle et al. (1976). However, more controlled research by Kucia, Drotar, Doershuk, Stern, Boat and Matthews (1979) opened the assertion to doubt. These investigators compared the family interaction of 15 well-adjusted versus 15 maladjusted cystic fibrosis patients, in terms of openness of communication, creativity, problem-solving, and support. The Unrevealed Differences Technique was used as a measure of openness, and although high interrater reliabilities were obtained, no significant differences were revealed on this dimension between family groups. A problem-solving motor task, the Simulated Family Activity Game, yielded a measure of positive support among family members, but again, no significant differences were found between groups. Since these statistically non-significant findings could be attributed to the considerable overlap between extreme groups, the relationship between adaptation and communicational openness remained unclarified.

Further indication that the overprotective mother/withdrawn father pattern is associated with dysfunctional adaptation derives from Boyle et al. (1976) and Allan et al. (1974). In assessing the individual and family adjustment of 27 cystic fibrosis patients ranging in age from 13 to 30 years, the first authors interviewed 21 mothers and 4 fathers, as well as each patient. Overall, 2/3 of the patient sample was judged competent in the performance of all daily tasks, and of these 18 individuals, 70% were honours students and those working were considered successful in their jobs. Although success of adaptation was not significantly related to severity of illness, the work status of the mother was significantly related to coping status, with non-working mothers, that is, mothers who stayed primarily at home, associated with only fair or poor success in 12 of 13 such cases. Work status of the mother was not related to severity of illness. The authors found evidence of "excessively infantilized" mother-child relationships in the nine cases judged poor in the performance of work, school and everyday tasks, and noted that 60% of all fathers were perceived by patients as distant and unsupportive (p.323). Over 1/2 of the patients who perceived their fathers in this way were judged unduly passive in their orientation to the world. Although the investigators do not provide the analysis, it is apparent from the table of assessment data included in their report that all three subjects who were entirely homebound perceived their mothers as overprotective and their fathers as either uninvolved or abusive.

In the Australian study, Allan et al. (1976) interviewed the mothers of 50 families having at least one cystic fibrotic individual. Those families in which the fathers were fully involved in family life, sharing in the decision-making and in the provision of health care, had greater likelihood of an intact marriage and less likelihood of behavioral problems with unaffected siblings. About 1/4 of the mothers indicated that the illness situation had strengthened the marital coalition, but 10 partial or complete marital breakdowns were also reported. Fully 1/3 of all fathers left the caretaking role entirely to their wife, and some mothers experiencing this predicament relied upon the emotional support given them by older unaffected sons and daughters.

The importance of mutual parental involvement, and particularly, father involvement, has been emphasized by other investigators. Rosenstein (1970), discussing his experience as a clinic director at John Hopkins Hospital, noted that few fathers seemed to be involved in treatment and household routines and that this situation frequently led to parental conflict which adversely affected patient adaptation.

Oppenheimer and Rucker (1980) concluded on the basis of questionnaire responses from 37 of 53 families polled, that home management was less effective when implemented by one parent alone, and that either a sound marital relationship or some other mutually supportive relationship for the caretaking parent, was most advantageous. The interview results obtained by Mikkelsen, Waechter and Crittenden (1978) added credence to these conclusions. And finally, the work by Kucia et al. (1979), cited previously, showed that fathers of the well-adjusted children were more flexible and supportive than fathers of the maladjusted children. In contrast, the mothers of well-adjusted children were less creative than mothers of the comparison group, suggesting that balanced parental teamwork was desirable. As a whole, families of better-adjusted children demonstrated greater creativity on the structured problem-solving task, whereas families of less well-adjusted children were more rigidly rule-oriented and less likely to consider alternative solutions.

Systems Thinking in Family Theory, Therapy and Research

The transition to perceiving and treating the family as a system has extended over the past forty years and been stimulated by contributions from diverse fields of endeavor. Many of the ideas have been developed in clinical settings, and have thus grown out of the inadequacies of the organic and psychodynamic perspectives inherent to the medical model (Haley, 1980).

The intent of the following section is to present current notions of the family as an interactional social system that evolves throughout its natural life cycle. Those dimensions of family interactional patterns which provide the analytical framework of this thesis are discussed, as are aspects of the functional and dysfunctional family.

Overview of Systems Thinking

As a prelude to examining specific systems applications in the realm of family theory and therapy, it will be helpful to overview several assumptions and implications of the systems framework. Whether or not systems thinking is regarded as a formal theory (Klir, 1972), a methodology (Klir, 1972), a paradigm (Laszlo, 1972), or a conceptual tool (Mattessich, 1978), when compared to traditional scientific thought, little doubt remains that it provides an alternative conceptual framework for examining complex phenomena, and can facilitate the exploration of problems not previously perceived (Von Bertalanffy, 1968). The importance of the framework underlying psychological research is often inadequately addressed, but it must be recognized that the assumptions within a researcher's conceptual framework essentially define the limits to the questions which are considered appropriate, and to the solutions or explanations which are entertained.

An abstract problem taken from the work of Watzlawick, Weakland and Fisch (1974) exemplifies this issue, serving as an analogy to the differing limitations of systems thinking and traditional scientific thought.

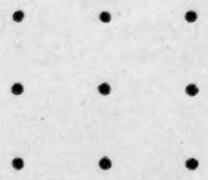

Figure 1. The Nine Dot Problem

The problem is to connect the nine dots shown in Figure 1 by four straight lines without the benefit of lifting one's pencil from the paper. The solution may be found in Figure 2 on page 39. As Watzlawick et al. (1974) note, most people who seek a solution render the problem impossible through assuming that it must be solved within the framework of the square. Thus their failure to resolve the problem arises not from the impossibility of the problem but from the limiting conditions of the framework within which a solution is sought.

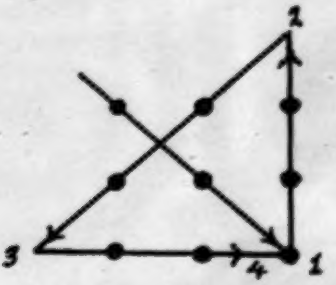

Figure 2. Solution to the Nine Dot Problem

How, then, does the systems framework go beyond the limitations of traditional scientific thought? Several dimensions can be identified, as follows: (a) Whereas traditional scientific thought is reductionistic, and asserts that the "variation of the total complex is the (physical) sum of the variation of its elements" (Von Bertalanffy, 1968, p.67), systems thinking asserts that the whole is more than the sum of its parts. (b) Whereas the reductionistic method purports to control variables other than those under study, the systems framework emphasizes that in order to understand a given phenomenon it must be considered "within the context of all completed circuits which are relevant to it" (Bateson, 1970, p.244). (c) Whereas traditional science is based upon a lineal notion of causality, such that a sequence of causes progresses over time without turning back upon itself, systems thinking operates upon the notion of recursive causality, such that the progression of time is de-emphasized and events demonstrate a reciprocal influence with no distinct beginning or end to the interactive sequence. (d) Whereas traditional scientific thought assumes that a value-free reality does exist, the systems framework recognizes that living systems demonstrate reflective capacities which cannot be observed directly but must be understood in terms of preference or norms which guide system behavior toward certain desirable goals (Von Bertalanffy, 1968; Laszlo, 1972; Mattessich, 1978). (e) Whereas traditional science asserts that knowledge is obtained by using objective measures from which all sources of bias have been eliminated (Neale & Liebert, 1980), the systems framework contends that scientific knowledge is not a pure truth or reality but "an interaction between knower and known" (Mattessich, 1978, p.273), in which the gap between the human mind and reality is bridged by "news of difference" (Bateson, 1977, p.240).

Undoubtedly one of the most profound aspects of the epistemological shift to systems thinking is the recognition that while a certain amount of carrier energy is required to sustain a living system, system regulation is achieved primarily by means of an ongoing information flow through feedback loops (Bateson, 1980; Buckley, 1968; Kantor & Lehr, 1975). Tomm (1981) has elaborated several dimensions of this development, as follows, using the term linear instead of the more correct word, lineal:

> Linearity is heavily rooted in a framework of a continuous progression of time. Linear explanations depend on careful differentiation of specific links which follow in a causal sequence. Notions of energy and force are often implied with linearity. Circularity, on the other hand, is more heavily dependent of a framework of reciprocal relationships based on meaning. Circular explanations depend on the relevance that elements have for each other and how a change in one implies a change in the other. (p.85)

The lineal notion of causality dates back to applications in physics by scientists such as Galileo and Newton, to the scientific scrutiny of events involving the transmission of physical energy over a given time period. Thus, lineal causality tends to be associated with quantification. Within circular causal networks the focus shifts to particular meanings in the present context. Meaning refers to "the significance of information to a system which processes it; it constitutes a change in that system's processes elicited by the information, often resulting from associations to it on previous experience with it" (Miller, 1965, p.57). Information transcends the time restraints associated with physical energy, and is not particularly accessible to quantification: a large amount of gossip might lull everyone to sleep at a cocktail party, while a panicked exclamation of 'fire!' leads to quite a different sort of action at the same party. Instead, information is more amenable to qualitative study, through reference to the repeating patterns of feedback characterizing complex systems (Watzlawick et al., 1967).

Information feedback is the "process by which a system informs its component parts how to relate to one another and to the external environment in order to facilitate the correct or beneficial execution of certain system functions" (Kantor & Lehr, 1975, p.12), and it has been described by Hoffman (1980) as the "basic, non-equilibrium ordering principle that governs the forming and unfolding of systems at all levels" (p.53). As system process is observed with particular attention to the ways in which changes in certain elements are associated with changes in others, the system is seen to consist of a complex of interlocking, overlapping feedback loops, some of which serve to maintain system output within a stable range, and others of which serve to change system output so that a new range of behaviors becomes the norm. The former type of feedback, commonly referred to as negative or deviation-counteracting feedback, is associated with system stability (morphostasis), whereas the latter type of feedback, called positive or deviation-amplifying feedback, is associated with system change (morphogenesis).

With the advent of cybernetics in the 1940's, deviation-counteracting feedback was recognized for its regulatory role, first in devices such as the thermostat and later in complex systems like the family. It was only in subsequent years that the powerful transforming aspects of deviation-amplifying feedback were recognized (Watzlawick et al., 1967). Phenomena such as vicious circles, self-fulfilling prophecies, and compound interest are examples of deviation-amplifying mutual causal systems in which a small, highly probable development progressively differentiates some aspect of the system until a large, highly improbable situation obtains (Maruyama, 1968). This process accounts for the characteristic equifinality and multifinality that complex systems exhibit (Von Bertalanffy, 1968; Watzlawick et al., 1967). Two or more systems may reach the same steady states from differing original conditions, or conversely, may reach different steady states from identical beginning conditions, and each system itself will provide the best explanation for how it evolved in that particular manner.

Introduction to the Family System

In spite of technological advances, the family remains the most basic unit of survival—socially, emotionally, and physically—in our culture. It provides the matrix of identity, shaping the individual's sense of self, of belongingness and separateness (Minuchin, 1974), and is the foremost vehicle of individual growth and need attainment (Feldman, 1981; Terkelsen, 1980).

As a system, the family unit occupies a particular level in the overall pattern of open, hierarchical systems (Tomm, 1980). Accordingly, each member represents a holistic system at the individual level, while remaining a member of the more inclusive family system at the next higher level. Similarly, each family can be viewed as both a system itself and a member of the more complex community system. Influences between and among systems move up and down the hierarchy; consequently, input about changes at the individual level makes a difference to functioning at the family level, and vice versa.

Like other social systems, the family is characterized by organizational complexity, openness, adaptiveness, and perhaps most vital of all, the capacity to process information (Kantor & Lehr, 1975) Unlike other social systems, however, the family encompasses special characteristics in terms of membership and affectional quality which imbue it with a particularly powerful influence in the lives of most people (Carter & McGoldrick, 1980; Terkelsen, 1980). By definition, membership in one's family of origin is permanent, granted at birth and retired at death; one cannot be fired, although some families make the effort, and any attempt on the part of the individual to leave the family field ahead of time is effectively hindered. Certain special types of family membership are granted, but even these are subject to complicated entry and exit procedures, such as marriage, adoption and divorce. As well, although the family system is undoubtedly task-oriented, primary emphasis is placed upon affectional loyalties, in terms of intimacy, "a condition of mutual emotional closeness ... among peers," and nurturance, "an exchange in which one or more family members receive emotional support and encouragement from another member or members" (Kantor & Lehr, 1975, p.47). These special aspects of the family system are contingent with the family life cycle.

The Family Life Cycle

Minuchin (1974) asserts that most families seen in therapy are experiencing transition difficulties, and are not pathological; Satir (1981) comments that the family has very little choice but to cope, one way or another, with the inevitable changes of life; Haley (1980) argues that in initiating therapy an understanding of the family life stage is more important than the presenting problem or diagnosis. Families frequently experience problems relative to confusion concerning changes in membership status or changes in task and affectional orientation. The general recognition of developmental-related problems has led to the formulation of the family life cycle, arranged around normative events such as marriage, the birth of a child, first school attendance, adolescence, retirement, and senescence (Terkelsen, 1980). Certain paranormative events, for example, separation, divorce, illness, and death, are also accounted for within this scheme.

During each phase of family life, developmental tasks associated with changing role demands and changing social-emotional needs can be identified. For instance, the adolescent family phase is dominated by shifts in the balance of responsibilities, fluctuations in the emotional intensity of relationships and increases in peer group exploration (Ackerman, 1980). Similarly, other phases of the family life cycle are characterized by a certain range of appropriate behaviors on the part of each family member, and transitions from phase to phase mean that a new set of appropriate behaviors must be acquired in order to stabilize the system. With each transition, the family system undergoes a step-function, or change in calibration, which can be likened to shifting gears in an automobile: the shift to a new gear facilitates a new range of speeds according to a new set of limiting gears (Watzlawick et al., 1967, pp.147-148). Families which shift gears smoothly seem able to acquire a new range of behaviors according to rules which promote flexibility, openness and change.

The Family as an Interactional System

The family is specifically an interactional system insofar as the members of the system, pictured as persons-communicating-with-other-persons, define the nature of their relationships through ongoing interaction. Each person-communicating-with-other-persons exists in the context of a hierarchical arrangement of systems, such that matter, energy and information are exchanged both vertically and horizontally with the environment (Watzlawick et al., 1967).

The family interactional system exhibits several features typical of open systems, as follows: (a) It demonstrates wholeness, in that all behavior is communicative, and not only influences, but also is influenced by, the behavior of others in the system. (b) It demonstrates nonsummativity, in that all behavior (communication) is reciprocally interdependent. (c) It is characterized by recursive feedback process, in that a part of output behavior is re-introduced to the system as information about output. (d) It demonstrates equifinality and multifinality, in that identical results are able to evolve from different origins, and vice versa, depending upon the particular organization of feedback processes.

Patterns of Interaction in the Family System

In the realm of family therapy and research, it is generally agreed that the appropriate methodology for examining the family system involves observing interactional sequences in order to identify repeating patterns (Bateson, 1980; Greenberg, 1977; Haley, 1976; Minuchin, 1974; Palazzoli et al., 1978a). In fact, Watzlawick et al. (1967) assert that the search for pattern is fundamental to all scientific endeavors.

These writers consider ongoing family interaction to be an example of a stochastic process, meaning that it exhibits a certain orderliness as it occurs, so that sequences which are observed over a period of time can be described in terms of showing redundancy, restraint, or in other words, pattern.

Pattern recognition and analysis. In this regard, Watzlawick et al. (1967, pp.48-117) have elaborated several tentative axioms of communication which provide a basis for pattern recognition and analysis. These will be applied to the subsequent analysis of family interview data in this thesis, and are delineated as follows:

1. It is impossible to not communicate, since behavior has no opposite. In any interactional situation all behavior is communicative in nature, whether verbal, postural, contextual, inflectional or otherwise. Even if one tries not to communicate, by totally ignoring or failing to respond to another, in doing so, one obviously communicates a desire not to communicate. Cast into a given interaction, then, one can (a) attempt to avoid defining the relationship by speaking gibberish, as a so-called schizophrenic might; (b) straightforwardly reject communication, perhaps thereby creating an awkward silence, but a

relationship nevertheless; (c) accept communication, and proceed to increasingly define the relationship; (d) disqualify communication, so that one appears to accept communication but then invalidates it one way or another, and finally; (e) communicate by way of symptomatology, so that responsibility for one's behavior is beyond self-control. Of these interactional behaviors, (c) and (d) were of greatest relevance to the current research. Most family members accepted communication, and proceeded to define their relationships with the interviewer and with other family members. However, some individuals found themselves obliged to communicate about matters they did not wish to, and disqualified their remarks or the remarks of others by contradicting themselves, changing the subject, misunderstanding, speaking in obscure styles, responding literally to metaphors, or by presenting inconsistencies, tangentializations, or incomplete sentences.

2. Each communication includes both a content level, which conveys information, and a relationship level, which provides information about how that information is to be taken, that is, which metacommunicates about the relationship between participants. The relationship level of a message may be expressed

verbally but is more frequently expressed by some non-verbal or contextual factor. In an interactional system, disagreement may occur on either level, but differences on the relationship level can only be resolved through metacommunication, by talking about the relationship. Confusion of content and relationship levels is demonstrated by marital partners who argue endlessly about aspects of everyday life, aspects which in reality only provide a focus, albeit unproductive, for pursuing relationship issues. As relationships are increasingly defined through ongoing interaction, each person's self-definition may be acknowledged in one of three ways: (a) T. may confirm or accept O.'s self-definition. (b) T. may reject O.'s self-definition, but in doing so at least asknowledges the reality of O.'s definition. (c) T. may disconfirm O. by indicating that O.'s reality is non-existent. A variation of disconfirmation is found in situations where one or more people demonstrate imperviousness, so that inaccurate awareness of the other person's viewpoint obviates a clear confirmation or rejection and leads to an interaction revolving around a pseudo-issue.

3. The character of a relationship is closely connected with the punctuation of communicational

sequences between participants. To the outside observer, an interactional situation appears as an unbroken sequence of exchanges, but each participant in the interaction tends to perceive and organize events according to one perspective only. Typically, this picture of events forms an unquestioned personal reality. However, it is possible for two individuals to punctuate the same event in entirely different ways, and such discrepant punctuations readily form the basis of an ongoing relationship struggle, especially if both partners are unable to metacommunicate. T. perceives O. as too demanding and aggressive, whereas to O., T. is simply too passive, a wimp at heart. Thus, they mutually disconfirm each other, and share a growing misery, at least until they are able to metacommunicate about their patterns of interaction.

4. Human communication occurs both digitally, wherein an arbitrary correspondence is found between the name and that which is named, and analogically, wherein the message is conveyed through a self-explanatory likeness, symbolically. The former is a sophisticated development which usually conveys the content aspect of communication and has thus been fundamental to the progress of civilization. In contrast, the latter, which conveys primarily the rela-

tionship aspect of communication, encompasses all non-verbal messages and is much more primitive and ambiguous. Any given analogic communication posits a tentative rule for the future of an interactional relationship, but the person receiving the message must punctuate it according to his or her own view of the relationship, and errors in translation from the analogic mode to the digital mode easily occur. An arm around the shoulder may be interpreted as a gesture of growing friendship or as a sexual innuendo, and the difference may be difficult but important to discern. In dysfunctional relationships, analogic communication typically emerges where the capacity to metacommunicate has broken down.

5. Interactional exchanges are classified as either complementary or symmetrical, with such classification determined primarily on the relationship level of communication. Complementary relationships are based on differences in behavior so that A. is giving and B. is receiving, or A. is one-up and B. is one-down. Symmetrical relationships are based upon equality of behavior, so that both A. and B. assert their right to the same type of behavior, for example, mutual blaming or mutual competition. The positions in mutually complementary and mutually symmetrical

relationships exist in relation to one another, and are not necessarily good or bad, or right or wrong, as both patterns necessarily co-exist and are able to provide participants with a source of confirmation. In a functional interactional system the two patterns tend to stabilize each other by way of flexible alternation or operation in differing circumstances. Dysfunctional systems tend to show both symmetrical escalation and rigid complementarity. In the former case, each member may try to be just a bit more equal, leading to an escalating competition which ends in deadlock and ultimately, mutual rejection, or is relieved by an alternation to complementary positions. In the case of rigid complementarity, one or both indfviduals may disconfirm the other's self-definition, leading to a sense of frustration and despair in the relationship.

Feedback patterns. In effect, complementary and symmetrical relationships exhibited in family interaction comprise the most basic recursive feedback patterns of the system, and are essential features of family stability, or morphostasis, and family change, or morphogenesis. Typically, the family system displays a balance of stability and change so that an overall stability is maintained but the family is able to accommodate new developments, of a small, ongoing nature, such as one member's mastery of a new skill, or of a more profound nature, such as the birth of a child, the coming of adolescence, or the onset of an illness (Terkelsen, 1980).

Deviation-amplifying feedback has the effect of escalating both complementary and symmetrical relationship patterns, but escalation beyond an acceptable range of behaviors is held in check when the "point is reached at which negative feedback is activated to resist further change in the same direction" (Tomm, 1980, p.11). Thus, deviation-amplifying and deviation-counteracting feedback combine to maintain an oscillating steady state in family interaction patterns. On those occasions during which escalation is not stopped, deviation-amplifying feedback promotes runaway behavior which either leads to a breakdown of the system or enables transformation to a more complex level of differentiation.

Feedback patterns are identifed by examining how differences are expressed in the system. Simple descriptions of people are not sought, but differences such as those between people, between reactions, between relationships, and between times, are explored. As Tomm (1981) has indicated:

> It is less useful to know whether father is affectionate than to know whether there is a difference in his affection recently compared to before, or whether there is a difference in his affection toward his daughter from that towards his wife. If father is most affectionate with his eldest daughter now, he must be less affectionate with his wife. (p.86)

Further, he notes:

> To identify a difference is to necessarily define a relationship between whatever is being compared. A relationship in this sense implies reciprocity. If mother gets her way more than father, father necessarily gets his way less than mother. Reciprocity, in turn, implies circularity. (p.86)

Bateson (1972) specifies "a difference that makes a difference" (p.315) is information; thus, by exploring differences expressed between family members one is defining patterns of information flow. Although complementary and symmetrical relationships are perhaps the most basic recursive circuits, feedback loops may also include three or more individuals and input from other systems.

Family rules. The orderliness of interactional patterns shown by the family is said to be rule-governed, and the family can thus be pictured as "a self-regulating system which controls itself according to rules formed over a period of time through a process of trial and error" (Palazzoli et al., 1978a, p.3). A rule is an inference which specifies the lawfulness demonstrated by patterns of interaction, and can be likened to a rule of grammar: Once a person has mastered a language, one is able to recognize and correct grammatical errors without knowing the actual grammatical rule. Family rules are similar in that they consist of a small group of statements which govern a wide range of behaviors and contexts, often out of the direct awareness of family members.

In the family interactional system each communicative behavior seeks to define the nature of a particular relationship, and the reciprocal communicative behavior accepts, rejects or modifies that definition. As the relationship is increasingly defined through ongoing interaction, the number of next possible behaviors is also increasingly limited. Rules thus become guides for "who does what, when, where, with whom, and how" (Barnard & Corrales, 1979, p.16), or "relationship agreements which prescribe and limit members' behaviors over a wide variety of content areas" (Feldman, 1981, p.146). They operate primarily on the analogic level of communication (Palazzoli et al., 1978b) and may be inferred in relation to feedback governing both stability and change, and in relation to other dimensions of the family, such as its hierarchical organization (Greenberg, 1977; Haley, 1976).

As the notion of subsystem boundaries is used by Minuchin (1974) it refers to a special subset of rules which apply to transactions involving family subsystems. According to Minuchin (pp.52-60), each member of the family belongs to a number of subsystems, but three major subsystems are usually identified: the spouse subsystem, which provides the adult architects of the family with a setting for mutual accommodation, supportive interdependence and socialization; the parental subsystem, which with the addition of the complex demands of parenting, is a transformation of the spouse subsystem; and the sibling subsystem, which functions to provide children with the opportunity to learn essential social skills. The specific membership of a subsystem is of less importance than the clarity of its boundaries, so that subsystem members are able to acquire and practise related skills, and fulfill their needs, without interference from the members of other systems. Minuchin (1974) states that subsystem boundaries are the "rules defining who participates, and how" (p.53), operating to protect children from inappropriate parental interference, so that children can learn to co-operate and negotiate with one another, and are not cast into roles inappropriate to their age level. Similarly, adequate parental subsystem boundaries function to keep the children out of the master bedroom except on occasions such as Mother's Day.

Functional and Dysfunctional Family Systems

Open systems in general show an ever-increasing movement towards differentiation and complexity, and family systems are no exception as they accommodate to the changing needs of each member while evolving through the family life cycle. Accordingly, it is the family system that fails to accommodate to change, and finds itself trapped by inappropriate patterns of interaction, that is usually identified as more dysfunctional (Satir, 1981; Tomm, 1980).

The foregoing discussion of the systems interactional framework has implied several aspects of functional and dysfunctional family systems. More optimally functioning families show qualities such as (a) congruence between content and relationship levels of communication, with high amounts of confirmation shown in communicative interactions, (b) exact and direct digital communication, so that idiosyncratic methods of analogic expression are not required, (c) clear agreement and mutual acceptance with regard to the punctuation of events, (d) flexible participation in both complementary and symmetrical interaction patterns by all family members,and (e) the ability to metacommunicate, so that conflicts, disagreements and differences can be openly discussed,resolved and accommodated (Watzlawick et al. 1967). In addition, more optimally functioning families typically share a warm and caring feeling tone, so that each individual is valued and respected, and inevitably the parental coalition of such families sets the standard for the remaining members (Goldenberg & Goldenberg, 1980).

Regardless of their placement along the continuum of functioning, all families interact in patterned ways which are rule-governed. However, more optimally functioning families demonstrate rules which promote a more efficient, smoother kind of stability for the whole unit, while facilitating accommodation to individual changes implicit to the family life cycle. Such families have rules which allow the rules to be negotiated. More dysfunctional families demonstrate rules which regulate stability, but in such a way that the family seems more disorganized, inefficient, and unsatisfying. Accommodation to individual changes may be impeded or prevented in order to maintain the family as a unit, and if rule negotiation is prohibited, changes to more functional interactional patterns may not be possible from within the system.

Summary of Related Research and Literature

In summary, the findings from several different perspectives have increased the understanding of adaptation to chronic illness and disability. Social role theory provided the basis for exploring illness-related role disruption in the family, and spawned research which has suggested a curvilinear relationship between severity of illness and role disruption. The social learning perspective incorporated social role ideas in the formulation of a treatment model which has shown success when combined with other therapeutic modalities. Within this model, increasing recognition is granted to the notion that adaptation is influenced by social context.

Research from the perspective of rehabilitation psychology has frequently explored the causal relationships presumed to exist between specific disabilities and specific personality patterns, and between severity of disability and degree of psychological maladjustment, No one factor which exerts a predominant influence on individual adaptation has been discovered, and in fact, the research suggests that various combinations of multiple factors could be important from case to case. It is therefore reasonable to conclude that individual adaptation to physical disability and illness demonstrates extensive variability.

The significance of the family in promoting functional adaptation has been widely recognized, and a number of studies have suggested that the way in which a family organizes itself to provide health care is of vital importance. However, family research in general has suffered from a lack of adequate methodologies and perspectives through which to further the understanding of family and health complexities. Even system-oriented research, which is of particular interest because the conceptual framework accounts for complexity and opens a number of possible intervention points, has been plagued with a vaguely-defined and confusing array of concepts from one study to another.

Research developments in rehabilitation psychology have been paralleled by research concerning psychosocial adaptation to cystic fibrosis. Wide variations of emotional functioning and personality patterning have been recorded, not only among cystic fibrotic patients but also among their family members. Early findings which indicated widespread academic underachievement and personal maladjustment have more recently been disputed. Again, the vital importance of the family is often recognized but investigations have been hindered by the lack of an appropriate research framework. However, certain studies have been suggestive with respect to the family and adaptation to cystic fibrosis: More dysfunctional adaptation has been associated with an overprotective mother/withdrawn father constellation, and with less open communication within the family, while more functional adaptation has been associated with mutual parental involvement and support, and with more open communication within the family.

In conclusion, the systems interactional framework, which is based upon assumptions profoundly different than those underlying traditional scientific thinking, has been presented as an appropriate perspective from which to study family complexity in a health care context. Pattern recognition, based upon observations of information flow, or in other words, upon identification of differences that make a difference, constitutes the essential method, and the analytical framework is provided in terms of specific dimensions of communicative interaction. While certain recursive feedback patterns promote family stability by maintaining the behavior of individual members within a range defined as mutually acceptable, other recursive feedback patterns promote family change by influencing individual development toward increasingly complex differentiation. These repeating feedback patterns demonstrate a lawfulness such that rules can be inferred about the operation of any specific family interactional system. The present study focuses upon rule-governed feedback patterns revealed by families from which a relatively independent cystic fibrotic individual has emerged.

CHAPTER III

METHOD

General Procedure and Design

In this study it was the writer's intent to ascertain: (a) patterns of family interaction in the context of cystic fibrosis, and (b) the efficacy of the systems interactional framework as an approach to research. Audiotape samples of interactional data were obtained from three volunteer families by means of a semi-structured interview, and as the study proceeded, the writer's observations and impressions of the research process were recorded in writing. All data were subsequently analyzed with reference to four research questions (see p.5), to discover similarities and differences among relatively functional, independence-promoting families, and to elucidate limitations and advantages of the research system.

As noted by Neale and Liebert (1980), a single case methodology is acceptable in those situations in which new methods are being demonstrated and new hypotheses are being sought. As well, it can be argued that the application of a systems framework for understanding the complexities of family interaction requires intensive consideration of each case

(Kantor & Lehr, 1975; Watzlawick et al., 1967).

Since the method of this study involved the description and analysis of qualitative patterns, no quantitative measurements were presented. In fact, given the assertion tendered by Watzlawick et al. (1967) and supported by Judson (1980), that all scientific endeavors are based upon the recognition of patterns, quantifiable or otherwise, the notion that measurement and statistical manipulation are essential to scientific work was specifically rejected. Quality and quantity are aspects of the same dimension, namely, difference, and in the present research, differences (and the lack thereof) between one time and another and between one family and another, were carefully noted.

Sample

The sample consisted of three volunteer families, each currently containing two natural parents and at least one cystic fibrotic individual between 18 and 22 years of age. The adolescent and young adult patient group was selected with the expectation that by this age the individual would have attained considerable independence from the family of origin; in fact, it can be assumed that the developmental task of the family with children of this age is to facilitate appropriate disengagement of such offspring from the nuclear family (Carter & McGoldrick, 1980).

The individuals with cystic fibrosis included two males and one female, and all were free of serious medical conditions not directly associated with cystic fibrosis. Since the focus of the study was upon relational rather than internal variables, factors such as intelligence and disease severity were not considered as essential to the nature of the investigation.

Subject families were secured with the assistance of the local Cystic Fibrosis Foundation. Subsequent to the writer's submission of a brief proposal, the Director of this group discussed the research with a number of families who seemed to fit the criteria, and composed a list of those who expressed an interest in voluntary participation. Of the four families then contacted by the writer, three were finally interviewed while the fourth declined on the basis of having been overexposed to research. By limiting the study to a small number of subject families it was possible to obtain a more complete picture of each family and to evaluate the data in greater depth, while at the same time allowing for some comparisons.

Interview Schedule

A semi-structured interview (Appendix B) was designed by the writer, with the help of an experienced counselling psychologist (Vander Well, 1981) to obtain: (a) basic background information, (b) descriptions of specific interactional sequences which had arisen in relation to events or issues such as time of diagnosis, treatment routine, adolescence, and career plans, and (c) actual examples of family interaction. As soon as possible after each interview, care was taken to record the interviewer's observations and impressions in writing.

The interview was developed and conducted according to methods proposed by Palazzoli et al. (1980) and Tomm (1981) to assist others in the proces of gathering meaningful information about family interactions. Palazzoli et al. recommend use of an essentially triadic model, in that "a member of the family is invited to describe in what way yet another family member reacts to that reaction" (p.10). Thus, each individual was asked not only about reactions to a given situation, but also about perceptions of others' specific reactions with regard to that same situation. For each event or issue, questions were directed toward eliciting a description of differences in behavior, before an event as compared to after an event, and between one person and another person (Tomm, 1981).

By obtaining a picture of interactional sequences displayed by other family members, this method of interviewing sought to circumvent individual resistance to describing involvement in intimate relationships. As well, through rotating series of questions to different participants, the interviewer remained essentially neutral to the whole family while stimulating information-giving by taking up successive alliances with each family member in turn.

Since it was recognized that the writer's interviewing skill would affect the quality of data obtained, the interview schedule was practised extensively with non-subjects until an acceptable level of competence, as judged by the writer, was attained.

Data Collection Procedures

Semi-structured interviews were arranged and conducted in accordance with the following procedures:

1. During a preliminary telephone contact with each family, the writer provided details regarding himself and the study. Participation was defined as voluntary and it was emphasized that the interviewer sought to learn how the family unit had accommodated

itself to the illness situation, and in particular, how it had used its strengths to promote independence.

2. Mindful of Tomm's (1981) comment concerning the exponential increase in the amount of information with the addition of each extra family member, only the identified patient and the parents were interviewed, although information regarding interactions of other family members and other significant people was frequently elicited. Emphasis was placed upon the importance of obtaining each participant's perception of reactions and accommodations.

3. During the signing of consent forms (Appendix C) the interview situation was defined as confidential, the necessity of taping was matter-of-factly explained, and commitments were made to provide feedback to subject families upon completion of the research.

4. In the opening to each interview, participants were asked to listen very carefully when someone else was asked a question, and when asked a question themselves, to think about it carefully before telling every detail.

5. Every effort was made to establish rapport with family members, through using preferred names, by

focusing upon less threatening information first, and by respecting the right of informants to withold information as necessary.

6. Whenever cues were observed which suggested there were objections or additions to whatever one person had stated, the interviewer asked other participants if they had anything more to add.

Data Analysis

Typed verbatim transcripts, together with audiotape recordings and the written record of interviewer's observations and impressions, were submitted to analysis. As the writer gained experience with the interactional frame of reference, it became apparent that the content of interview data was of less importance than the style of family presentation. This understanding affected that section of the analysis addressed to the first three research questions. Thus, the patterned ways in which family members interacted with each other and with the interviewer, during the actual interview, were explored, and these patterns were corroborated with the patterns of interaction described by family members in relation to past events. This part of the analysis proceeded in terms of the dimensions of communicative interaction described in the previous chapter. Recurring patterns of symmetrical and complementary relationships received particular attention, but consideration was also given to (a) patterns of accepting, rejecting or disqualifying communication, (b) patterns of congruency between content-oriented, digital communication and relationship-oriented, analogic communication, (c) patterns of confirming, rejecting or disconfirming communication, and (d) patterns of punctuation agreement. In consonance with Watzlawick et al. (1967), pattern discovery and analysis were accepted as the essential modus operandi, and it was assumed that each family system provided its own best explanation.

The final section of the analysis addressed the limitations and advantages of the interactional framework as a system of research in the present study and was thus a meta-analysis. It was concerned with the question of how well the system's interactional methodology and related concepts accounted for the issues spoken to in the analysis of the first three research questions. The data for this section of the analysis included the writer's experience as participant observer, in addition to all data and literature previously mentioned. Becker (1958), elaborating upon the value of participant observation, emphasized that it is particularly useful when the nature of a problem is not well-understood beforehand, but instead, increasingly unfolds as the research endeavor proceeds.

CHAPTER IV

FINDINGS

Interviews were completed during June and July of 1981, and averaged approximately 1½ hours in duration. All three interviews took place at the participating family's home.

In this chapter the interview findings are explored in a case-by-case format. Each case presentation includes a description of basic family information and the interviewer's immediate impressions, and is followed by a documented review of family interaction patterns promoting system stability and change. All case summaries conclude with a succinct statement of the rules which can be inferred to account for aspects of the functioning of that particular family system. Where interview dialogue is included as evidence, the abbreviated headings I, M, F, D and S denote Interviewer, Mother, Father, Daughter and Son, respectively.

The A. Family

The A. family interview, attended by Mr. and Mrs. A., aged 68 and 55 years respectively, and their daughter D., aged 22 years, revealed a very interesting family in which the parents had excelled at encouraging independent adaptation on the part of their daughter. Their son, aged 31 years, married, and professionally employed in the same city, was reportedly free of cystic fibrosis. Another daughter, two years younger than the son, had died of the disease at the age of seven, when the present daughter was almost one year old and had been a cystic fibrosis patient for over five months.

The interviewer was surprised that the A. family agreed to participate in the research, since Mrs. A. seemed to express doubt and caution during the initial telephone contact. During the interview itself the family impressed as generally friendly, good-humoured and a little reserved. Mrs. A. and D., in particular, both showed a mild sense of humor, although laughter was frequently of an uneasy tenor. Mr. and Mrs. A. appeared more tense and reserved than did D., the most talkative of the three. The interview took place in the large family living room, with Mrs. A. sitting in a separate chair opposite her husband, who sat on the couch beside the interviewer. D. occupied a chair apart from her parents, opposite the interviewer. It was observed that when D. talked she often held contact with her mother, and that both women frequently laughed together and would signal by either whispering or gesturing whenever either one had anything to add but was not directly involved in the conversation.

Overall, members of the A. family were involved in many activities independent of one another. Mr. A. reported that he had previously worked in a professional capacity, but now spent his retirement playing or watching sports activities, most often with friends, his son, or his brother. As well, he sang in a chorus, often played the piano, busied himself with outside housework, and did "quite a bit of shopping" since Mrs. A. did not drive. Mrs. A. confirmed that she was the family homemaker, although had also worked at her profession in the early years of their marriage. During the summer, she golfed with friends twice weekly, and in the winter, attended a church study group once a week in addition to her regular involvement with the church women's organization.

Together, Mr. and Mrs. A. occasionally attended a sports, entertainment or social event, and shared the gardening. As well, Mr. A. was involved in community work which Mrs. A. supported by doing the typing it required. According to Mrs. A., her husband often prepared his own breakfast and lunch, but they seemed fairly flexible in such matters depending on activities planned for the day. As a family, the A.'s attended church on Sundays, and both parents emphasized that they had always included D. in their annual vacations. Mrs. A. seemed stuck for words when asked about activities she shared with her daughter, but Mr. A. interjected that they went shopping together "quite a bit", and that D. had her own car.

D. thought that having cystic fibrosis had been significant in limiting her physical activities "a bit", especially as a teenager, but otherwise reported that she lived a reasonably independent lifestyle and entertained plans of moving out to live with a friend when she had some money saved. D. had just completed a professional university degree, and during three previous summers had maintained full-time employment. She was currently looking for either full- or part-time work in her profession, and listed extensive involvements in other activities outside the family. Of these, a Bible study group seemed of special importance, as many of her own-age friends from that group were very supportive, and had even assisted with her physiotherapy on several occasions in her parents' absence. Around the home D. reportedly helped with some household chores, and made her own lunches and some of her own breakfasts. Occasional sporting and entertainment events were attended with one or the other parent.

Interactional Patterns Promoting Stability

It has been noted that members of the A. family led independent lives with a modicum of shared involvement. An identical organizational style was illustrated consistently throughout the interview. Subtle and unclarified discrepancies were tolerated in the punctuation of events, and family members showed considerable tolerance of disqualification and disconfirmation in the discussion of many issues. At times a strong sense of symmetrical competitiveness was perceived by the writer, but all interview participants seemed to observe tacit agreements regulating conflict and metacommunication. Although the members of the A. family were eager to communicate, they protected both the interviewer and themselves by carefully minimizing, obscuring and not mentioning those aspects of family life which may have been controversial and upsetting. As well, the correspondence between content and relationship levels of communication was not always congruent, and family members showed special patterns of communicating non-verbally (e.g. mother-daughter non-verbal contact).

Both Mr. and Mrs. A. defined their relationship in a highly symmetrical manner, although Mr. A. held the position of rational organizer and tried to keep the "two women in order", while Mrs. A. held the less overt position of communications manager. Together, they had developed sensitive skills which enabled them to punctuate their relationship in vague, seemingly independent ways and to disconfirm one another while managing their differences so that open conflict did not become a problem. Stability between them was maintained by directing the topic of conversation, by changing the subject, by neglecting to pursue differences openly, by presenting vagueness or memory lapse, and occasionally, by supporting the interjection of new information by their daughter. For example, the following exchange concerned changes in Mrs. A.'s routine at the time of D.'s adolescence:

> I: Right. How did your wife's routine change at that time?
> F: Not very much, I don't think.
> M: I'm trying to think, did you start having your physio before dad retired?
> D: H'mm.
> F: Yes, oh yes.
> M: So you'd still be working?
> F: Yes, I'd still be working at my job.
> M: But you didn't have as much physio then as you have now, did you?
> F: Almost.
> D: H'mm.
> M: You'd do just maybe the one side, wouldn't you?

F: Maybe about half an hour -
M: It wasn't an hour -
F: (Overlapping) More than half an hour
at night, it wasn't an hour and -
D: I had it right after school sometimes,
though.
M: That's right.
F: Of course she slept in this tent too,
and sometimes -

At other times, symmetrical interactions between Mr. and Mrs. A. were maintained by imperviousness toward one another. The exchange below took place when Mr. A. was asked to describe changes in his wife's routine when D. had entered grade school:

F: (Pause) Well, there wasn't that she had
more work to do.
M: I went back to temporary work for awhile
when D. was in grade one.
F: Yes, but you see the school was only about
two-and-a-half blocks away, and sometimes
I'd take D. to school -
M: Yes, that's true, in cold weather he
always took D.

As this conversation continued, Mrs. A. reiterated that she had gone back to work at this time, but Mr. A. did not acknowledge an awareness of her comment and continued to state that there had been little change in her routine.

On another occasion, Mr. and Mrs. A. engaged in exchanges defining their relationship symmetrically, but ended the sequence on a humorous one-up, one-down note:

I: There wasn't very much change in your routine except that you had to tighten it up?
M: No.
F: Yes.
M: She went to play school, and she appeared to be the same as all the other kids.
F: She even took figure skating and swimming, you know.
M: (Reprimanding tone) Yes, that's a little later.
F: Was it? (General laughter)
M: Yes. (Laughter continues)

The symmetrical emphasis of Mr. and Mrs. A.'s relationship seemed to emerge from the potentially complementary positions they held in the family: while Mrs. A. appeared more emotionally-oriented, Mr. B. appeared more rationally-oriented. However, these positions were not readily acknowledged, and it seems likely that Mr. and Mrs. A. shared a punctuation discrepancy along these dimensions, so that Mr. A. perceived his wife as too emotionally reactive and not rational enough while Mrs. A. perceived her husband as too rational and not understanding enough. The evidence for this configuration was somewhat subtle and vague. For instance, whereas Mr. A. simply described his leisure activities with no particular emphasis upon companionship, Mrs. A. showed a much greater concern for activities she and her husband shared. As well, both Mrs. A. and D. enjoyed a good chuckle when mention was made of

Mr. A.'s more rational list-making abilities. It seems reasonable to surmise, however, that this relationship pattern represents a major feedback process serving to distance these individuals from one another as they remain entrenched within mutually complementary positions. This situation seemed to lead them into symmetrically competitive interactions in the presence of the interviewer.

Both Mr. and Mrs. A., and D. appeared cautious when talking about one another, and their sensitivities in this regard undoubtedly assisted in maintaining system stability. The following exchange, which originated in relation to a change in medication routine, illustrates several points:

I: What was your wife's reaction to that change?
F: Well, she -
M: (Interrupting) I maybe sometimes have the reputation of being overprotective of D. when - (laughs) when she was sick in school, do you think, with your friends, D.?
D: H'mm.
R: Maybe.
M: They wouldn't realize necessarily that D. had C.F., and they thought maybe because I had lost a child before that I was an overprotective mother I think.
I: What was your wife's reaction in D.'s starting school?
F: Well, I think she was probably looking forward to it, as much as anything, you know.
I: How did she indicate that she was looking forward to it?

F: Well, she might have been a little more
relaxed - (chuckles) I don't know, I can't
remember. (General laughter)
I: I know I'm really stretching your memory.
F: 'Cause D. would be away for a few hours
in the morning and afternoon.
M: (Laughs) Are you insinuating I was trying
to get rid of her? (Mother and daughter
laugh)
I: Well, these changes -
F: (Interrupting) Yes, I don't think there
was much change really.

Mrs. A. was particularly skillful at defining situations her way by placing herself in the one-down position to elicit agreement, and such definitions were usually accepted by the others. As well, when comments became too direct, and were not qualified in some way by the speaker, humorous remarks effectively limited further deviations.

Throughout the interview it was apparent that Mr. and Mrs. A. shared similar punctuation regarding their authority to protect D. For example, when D. was describing her attendance at sporting events, her mother noted that the weather wasn't always suitable, and Mr. A., when asked to describe the new activities which D. sought involvement in as a teenager, mentioned the difficulties inherent to swimming. Likewise, both Mr. and Mrs. A. emphasized that D. had not been a "headstrong" teenager and had more or less accepted the restrictions placed upon her. Throughout the interview, D. did not dispute these comments to any great extent, at least not verbally, and on those occasions she was asked to differentiate between the reactions of her parents, clearly chose to accept their definition of minimal difficulties. For instance, when asked about her parents' reactions to her new teenage activities, D. replied:

> D: Well sometimes I think maybe they're a little overprotective but I think they're just concerned parents. You know they wanted to know what I was doing, and who I was out with, or -
> I: What particularly did they do that made you think that they were overprotective
> D: H'mm, that's a good question (laughs uncomfortably). H'mm (long pause).
> I: If you can't readily think of anything that's fine.
> D: I can't think of anything specific, that's just the feeling I had.
> I: Yes. Were their reactions the same?
> D: You mean each?
> I: Yes.
> D: Both of them, the same? To what I was doing?
> I: Yes. When you wanted to go out and do something, would they react in the same way?
> D: I think basically - I don't think one was more worried than the other or I think they, you know, we all tried to compromise, and -

When commenting on her own activities, D. considered herself equal to her parents, but when talking about her parents she became more indirect, and any comment which may have been construed as critical was either presented in the context of humor or disqualified with an accompanying remark. In showing such deference,

D. was not assuming a complementary one-down position as much as she was observing a fundamental family rule.

In relation to D., Mr. A. seemed less likely to deviate from his protective position. For instance, he had objected to D.'s choice of occupation, suggesting forcefully that she would be wiser to choose a less demanding type of work, and now that D. had successfully completed her training, he continued to assert that she could always get easier work. However, while Mrs. A. remained allied with her husband, she also appeared more sympathetic to her daughter, and their regular non-verbal contact suggested a common understanding was maintained about many issues. Mrs. A. noted that she had played a supportive role in relation to D. during periods of adolescent despair, and one can speculate that this mutually satisfying complementary relationship continued into the present.

Interactional Patterns Promoting Change

With regard to academic achievement, D. recalled that when she had been of school age both her parents had encouraged learning activities, and Mr. A. reported that his daughter had been a keen student right from the beginning. Since Mr. A. undertook heavy employment responsibilities in earlier years, D.'s mother had been most involved with facilitating school progress, but Mr. A. took the time to teach her about music, and this interest became an enduring and influential activity in later life.

D.'s career development during and after high school demonstrated a particularly interesting interplay of deviation-amplifying feedback. By grade 11 she had been playing and teaching music long enough that she was reasonably certain of her interests in this area. These interest patterns were supported by school counsellors, but it seems her parents, and in particular, her father, thought she should work at a less demanding secretarial position. However, D.'s personal certainty about her career choice was reinforced during a first year of university, and her relationship with her parents around this issue escalated as she resisted their mutual protective efforts. At the time of interviewing, this symmetrical battle for the right to self-definition was persisting with her doctor, who had recently shocked her with the suggestion that she work only part-time.

A final interaction pattern which led to the possibility of independent behavior was D.'s involvement in church activities. She indicated that through attending a study group she had acquired a very supportive group of friends her own age, and at least one of these friends had helped her with physiotherapy on several occasions. This situation had been "hard on the ego", but since the friends remained supportive and willing to help, it enable D. to plan an extended vacation independent of her parents. For the young adult with cystic fibrosis developments such as this are necessary steps along the way to independent living.

Family Rules

Based on interactional patterns promoting stability and change, the following rules can be inferred with regard to the A. family: (a) Mr. A. will be more rational while Mrs. A. will be more emotional, and discussion of these complementary positions will be prohibited. (b) From their respective positions of authority, Mr. and Mrs. A. will struggle to remain slightly one-up on each other. (c) Any undue escalation of competition within the family will be curtailed by any of a large selection of communicative manoeuvres. (d) Adequate parents will always protect their daughter. (e) Open conflict, disagreement and criticism will be avoided. (f) Open agreement will sometimes be avoided, since it may imply disagreement to another. (g) Criticism will be allowed if the speaker disqualifies the message. (h) Each person will have equal rights and authority to define relationships with other family members, but direct comments about feelings, about others, and about relationships will generally be avoided. (i) Self-expression and achievement outside the family will be allowed, and will be encouraged insofar as parental protective efforts are not violated. (j) Should family difficulties be recognized to any extent, they will be minimized.

The B. Family

The B. family interview took place at the family farm, over cups of fresh coffee and in a warm, friendly atmosphere around the dining table. The interview was sandwiched at the end of the school day, just before a quick supper and an evening baseball game. While Mr. B., aged 49, Mrs. B., aged 45, and their son, J., almost 18, participated in the interview, the youngest member of the family, a healthy 14-year-old daughter, worked in the adjacent kitchen preparing supper according to periodic instructions from her mother. A second son, who is 23 years old and also has cystic fibrosis, lives in a nearby city where he is married and works as a businessman. Another daughter died of cystic fibrosis when she was about

14 years old. At that time, J. was almost 11 and had been diagnosed for 6 years.

When first contacted by the interviewer, Mrs. B. expressed immediate interest in the project, and thought the family would take part providing J. was agreeable. While the interview was being scheduled during a subsequent contact, the interviewer was warned, lightheartedly, that J. "didn't like thinking too much". Throughout the interview, the family impressed the writer as openly expressive and exceptionally good-humored.

Overall, the members of the B. family led very active lives with high levels of mutual involvement. Mr. B. was clearly responsible for farm and business interests, and reported little involvement in household chores because of long hours attending to work-related demands. Mrs. B. remained clearly responsible for homemaking tasks but worked only an eight-hour day now that the children were older. While Mr. B. acknowledged a history of being more work-oriented, Mrs. B. revealed herself as a more people-oriented person, and she seemed to have had primary responsibility for caretaking and nurturing activities in relation to the children throughout their marriage. However, although these role responsibilities were clearly delineated, it was apparent that both Mr. and Mrs. B. had remained very flexible, offering high levels of mutual support. Their early family life had been so work-oriented that leisure activities had been curtailed, but the family orientation had changed in recent years so that Mr. and Mrs. B. now pursued many activities together, shared a circle of close friends, and were keenly involved in family-oriented activities. In addition, Mrs. B. was involved in her own sports activities with other women and devoted time to community work.

The B.'s son, J., was completing his final year of high school, where he had excelled in certain subjects, and was planning to undertake a professional program at university. In addition to full-time school and school-related activities, he drove his own car, worked about eight hours weekly for his brother, watched family sporting activities, and helped with chores around the house and farm. When asked about the significance of cystic fibrosis in his life, J. mentioned its limiting effects as far as physical activities and openly showed his emotional ambivalence about accepting his condition. It was reported that several relatives outside his immediate family had maintained a supportive and understanding relationship with him.

Interactional Patterns Promoting Stability

With few exceptions, participants in the B. family interview presented clear, consistent pictures of family accommodations and reactions throughout the phases of family life. High punctuation agreement was shown, as were high levels of congruence between verbal (content) and non-verbal (relationship) aspects of communication. In both symmetrical and complementary interactions, between and among participants, mutual support and confirmation were readily apparent. Each person was granted the right to answer specifically directed questions without interruption, although when a complementary one-down position was assumed by any one of the three, reciprocal support was elicited from others. Mr. and Mrs. B. in particular revealed their ability to talk directly about relationships and about people's reactions. Judging by requests for clarification and by supporting remarks made in relation to each other, all participants demonstrated high levels of listening ability.

It has been noted that Mr. and Mrs. B. managed the demands of farm and family life in a flexible, reciprocally supportive manner. Their response to the interview situation also reflected this style.

Mr. and Mrs. B. were able to shift smoothly from complementary interactions to highly symmetrical interactions, and vice versa, with both types of interaction showing mutual confirmation and remaining devoid of a sense of undue competition or rigidity. This style is exemplified by the following sequence:

> F: Well that's about the time he started playing baseball.
> I: H'mm.
> F: You know, as a ... 11, when did he start, 12, 11, 12? (To wife)
> M: 12, I think, yes.
> S: Yes.
> M: That was a good experience for him.
> F: Oh, I think it was a good experience for the whole family, 'cause it was probably the first time that we had taken part in any of the kids' activities.

As this sequence continues, Mr. B. described at length and without interruption significant changes in family philosophy and the reactions of his wife to such changes. Mrs. B. made one symmetrical remark, and responded supportively when her husband switched to a one-down complementary position. When another open question was asked, Mrs. B. embarked upon a description of other changes in their adolescent son's activities, defining a symmetrical relationship with her husband and a complementary relationship with her children. In doing so, they punctuated many developments identically, and where a minor punctuation discrepancy occurred, either made no issue of it or resolved the sequence in humor.

Certain exchanges illustrated the quality of fine-tuning in their relationship. For example, when Mr. B. was asked about changes in his wife's routine around the time of diagnosis, he described such changes symmetrically, but in a tentative, one-down manner, so that when asked to comment she could confirm his description and expand upon it, thereby adopting a symmetrical one-up stance.

Both Mr. and Mrs. B. were able to adopt the complementary one-down position in relation to one another, and such a stance was smoothly accepted as an essential aspect of the relationship. For example:

> I: What was your reaction to that way of communicating?
> M. Oh, I find it difficult, because I'm a talker, and he wasn't. I knew he wasn't when we got married, but he's much better.
> F: Still I'm not. (Laughter by all)
> M: Yes, yes, it's much better.
> I: What us males have to do!
> M: Oh, there's some males who do a lot of talking (laughing) but not father - but he's learned to open up.
> I: What was your reaction to living with a talker?
> F: (Stuck for words, laughter by all) Oh dear - well, I'm glad that one of us can talk - somebody can express their feelings. That can be very positive - that's probably why I married her.
> M: (Laughing) 'Cause I talked a lot. (Laughter by all)

Mrs. B. was obviously the emotional leader of the family, and Mr. B. openly acknowledged the contribution of her expressive abilities to their marriage while she in turn supported his expressive efforts. In the one instance where discrepancies were apparent between non-verbal and verbal levels, suggesting an event which continued to present perhaps confusing and painful emotions, Mrs. B.'s definition of the situation was accepted by the others and stability was thus maintained.

When general family issues were discussed, as when he was asked directly for his reactions, J. tended to respond on an equal basis to his parents. However, when asked to comment on differences between his parents, J. placed himself in a more complementary position and did not openly favor one or the other.

Certainly, a special aspect of his relationship to the family, and in particular, to his father, emerged from J.'s ability to bring out the good-humored fun inherent to a situation. For example, the following exchange concerned physiotherapy:

> I: What was your reactlon to that?
> S: To?
> I: Having to move, move, move ...
> S: Move, yes, well, for the first while it seemed pretty - h'mm, what's the word? (Softly) Useless? Oh, yes, probably for the first week I thought it was really good. I got to have physio, but then after it wore off it probably got (emphatically) boring, and I'd try to sleep on the board (laughing) so I wouldn't have to do the next step. (Laughter by everyone)

And in relation to his father, he noted:

> I: What was his reaction to giving treatment?
> S: Well, get out of bed, and go like hell - (laughter). Well, it just had to be done - (seriously)

It was apparent that J. sometimes resisted his parents' complementary definition of their relationship with regard to treatment and achievement issues, but symmetrical escalation was dampened by someone adopting a more complementary stance. For example, his resistance to taking pills had been met with a deviation-counteracting, business-like firmness, and he had learned to "get on with it". During vacations away from home, when forgotten pills could have become an issue, his mother had accepted his right to define the situation and an escalating conflict was thus avoided.

Interactional Patterns Promoting Change

Change in the B. family, in relation to achievement and other types of independent behavior, was expected and mutually encouraged by Mr. and Mrs. B. It appeared that J. also received a sense of satisfaction from his own efforts, and certainly he observed the sense of astonishment and pride his father showed about his unanticipated level of academic success. If J. wanted to do something new, parental support was readily forthcoming for whatever effort he put forth. For example, J. had been encouraged to play baseball when he had expressed an interest, but was obliged to ride his bike to the games before his parents would agree to pick him up by car.

A particularly interesting feature of the B. family was the dramatic change which had occurred in the family orientation to work and play over the years subsequent to their first daughter's death. Prior to this event, the family apparently placed work first, and leisure play and family enjoyment further down the list of priorities. But somewhere along the way, at a point it is not possible to determine, a transformation of this powerful family rule began, so that a complex interplay of deviation-counteracting and deviation-amplifying influences over a long period of time led to a complete re-ordering of family priorities. These influences included the following: (a) Mrs. B. was present as an emotionally expressive, people-oriented influence. (b) Their daughter's death intensified Mr. B.'s awareness of feeling he had not been as fully involved with the family as he would have liked, and this influence dampened his preoccupation with work while heightening his family concerns. (c) In the process of coping with the death, several couples became very supportive friends. (d) Financial pressures which had been heavy in earlier years probably eased off as the farm became more established. (e) Mr. B. and J. had established a warm relationship so that Mr. B. became more involved in J.'s routine physiotherapy treatments. (f) J. became involved in baseball, and through attending his games, Mr. and Mrs. B. widened their circle of friends. Mr. B. stated:

> F: And then - I don't know, it just kept mushrooming after that. We met a lot of different people and we went out of our way to meet people. (Looking to wife) Am I not correct in that assumption?
> M: H'mm. Oh, yes.

And again later:

> M: So it really does depend on the people you meet. We've made some very good friends over the years who've helped us through -
> F: That's what I was coming to. I think we developed a circle of friends, about three or four close couples the - especially during - after our daughter's death, really, you know, bore us up and -
> I: Stood by you.
> F: Stood by you. I would probably say that our daughter's death was maybe the turning point in our family relationships. Looking back on it now, after she died we decided to do things together, and spend more time with the family, and -
> I: Sort of like it intensified your life, or made you intensify it.
> F: Yes. Other things that were priorities before we just - just shunted to the side and they weren't so important any more.

Thus, with transformation at the level of a basic family rule, it can be speculated that this family's experience of life together is now richer and deeper than at any time in the past.

Family Rules

On the basis of family interaction patterns promoting stability and change, the following rules can be inferred about the B. family: (a) The parents will share executive authority, together or more independently, depending upon the issue, but both will remain open to input from others. (b) Work will remain important, but family enjoyment will be of greatest importance. (c) Each day will be lived as it comes. (d) Each person will have the right to self-expression and the right to be heard by others. (e) The open expression of ideas and emotions will be permitted and encouraged, so that individual growth will be facilitated and the rules can be changed. (f) Each person will have considerable right to comment on others and on their relationships with others, but parents will have more rights and authority in this regard. (g) Each person will have clear responsibilities, but will offer mutual support as required. (h) Humor will be valued in any situation it can be found, as humor helps to make the best of things. (i) The family will remain open to extrafamilial support and other outside influences. (j) Each person will be encouraged to develop individual potential as much as possible.

The C. Family

The participants in the C. family interview, Mr. C., aged 65 years, Mrs. C., aged 46 years, and their son S., aged 18 years, engaged the interviewer in a lengthy, lively, and entertaining session. It was learned that a fourth member of the family, a 22-year-old daughter, lives and works in a nearby town and is free of cystic fibrosis. Apparently a second daughter died of cystic fibrosis at about the age of three, when S. was just one year old. The diagnosis of cystic fibrosis was made on S. at the age of five months, and had been a shock to his parents although they were somewhat prepared by previous experience.

When first contacted by telephone with regard to participation in the research, Mrs. C. was quite certain the family would be interested, providing a time agreeable to their busy schedule could be arranged. This requirement was finally satisfied by meeting on a Sunday morning, and when the interviewer arrived Mr. C. and S. were helping Mrs. C. clean the kitchen floor. The interview took place in a well-used living room, over coffee and hot rolls, with the interviewer sitting on a couch opposite S., who sat in a separate chair. He was flanked by his mother in a chair to the right, and his father on a second couch to the left. Throughout the interview, the C. family impressed as energetic and fun-loving, and the family's warmth extended to the point of inviting the writer to tour the farm operation and to stay for lunch.

Overall, family members showed a high level of mutual involvement around farm-related activities. Mr. C. indicated that the management of their mixed farm was his full-time responsibility, although he received assistance from both S. and Mrs. C. Primary responsibility for housework was held by Mrs. C., although she received help from both men. Mrs. C. confessed to being a "workaholic", and this trend was confirmed not only by her son and her husband, but also by the fact that she maintained full-time employment outside the home as an administrative manager. This position required long, variable hours and periods of travel which meant leaving the men to care for themselves, but she expressed great enthusiasm about the work. It was apparent that

Mrs. C.'s career had always been important to her, but no more so than had her family.

Members of the C. family laughed wholeheartedly at the mention of leisure time, but did admit to enjoying family vacations, and going to the lake or skiing together. Mr. C. and S. both enjoyed long hours of reading, whereas Mrs. C. preferred to keep busy: She indicated that gardening and community work provided pleasant alternatives to her full-time job.

S. seemed to pursue a full and relatively independent lifestyle. He maintained responsibility for his own medications, and in the past had travelled to a distant Canadian city by himself. S. had completed his first year of a professional program in university while living on his own in the city, and appeared enthusiastic about undertaking the second year. For the duration of the summer he held employment as a full-time laborer, and helped his parents with farm and household chores. Aside from his leisure reading, a pastime shared with his father, S. often drove his car to a relative's summer cottage to swim and to water-ski. He noted there had been nothing special about having cystic fibrosis except perhaps the extra attention he had enjoyed at times.

In addition, he had experienced opportunities to meet people he wouldn't otherwise have met, both through periodic hospitalization and through involvement with the Cystic Fibrosis Foundation.

Interactional Patterns Promoting Stability

The interactional style exhibited by members of the C. family during the interview reflected the active involvement portrayed in their everyday lives. The interview was characterized by a high energy level, playful bantering, and frequent instances of two or more people talking at once. Family members were very mutually responsive, and this aspect stimulated tangents by one person or another, or the whole family, leading to the exploration of various side issues. Surprisingly, the initial topic of conversation would later re-emerge, and nobody would have been lost in the animated discussion. Content and relationship levels of communication were congruent, and laughter, joking, and attending behaviors were all highly confirming. Although styles of articulation were different, each person participated in a more or less equal fashion in the interview, moving easily back and forth from complementary and symmetrical positions in relation to others. Events and issues typically received identical punctuation, and where differences existed, open negotiation and discussion were immediately undertaken.

Throughout the interview Mr. and Mrs. C. articulated very different communicative styles, but in general their relationship seemed balanced and mutually accepting. Exchange involving both of them often proceeded as mild struggles, but ended with either humorous comments or the adoption of complementary positions. For example, the following interactions occurred during discussion of the time of diagnosis:

I: Okay. What changes were there in her routine at that time?
F: Nothing to speak of right at that time, I mean it might have affected her later or something.
M: (Overlapping) Well, I don't know in what sequence it happened, but I quit work. You see, I was working in those days.
F: Yes, but -
M: Oh, I worked. You see, between one daughter and the other, I went back to work and then when our second girl was born, then I quit work until after she died.
F: Yes, but (overlapping) I know that, that was -
M: (Overlapping) I went back to work then.
F: (Overlapping) That was as far as quitting work. You were quitting anyway.
M: M'hmm.
F: That was quitting anyway. It's just that it could have had a bearing on when you went back to work.
M: But I went back to work -
F: (Interrupting) But I'm saying there was no immediate change.
M: (Agreeing) No, no.

I: Do you think you worked harder?
F: (Laughing) I don't know.

M: Possibly so.
F: We get in the habit if there's something bothering you, you can't be enjoying yourself, well, better go and work for awhile.
I: Sure.
M: Yes.
F: Nothing else, at least you get the work done. (General laughter)
I: When you -
M: (Interrupting) He tends not to show -
F: (Interrupting) I get used to thinking you're not supposed to expect everything to go right, so when it doesn't go right, I figure, well, that's normal for the course.
M: Yes. He accepts life day-to-day as it comes, you know, probably more so than I do.

Mr. and Mrs. C. shared equal rights to define their relationship, and tended to accept their differences openly. Whereas Mr. C. made more teasing, humorous remarks, Mrs. C. was more serious and less easygoing. However, she responded positively to humor, often with quips of her own, and he became more serious on many occasions. At such times, he resembled a rambling philosopher, and was granted full reign to pursue his ideas by other family members. Mrs. C. was much more to the point, and emerged as the clear metacommunicative leader of the family. For instance, when asked about her son's reaction to starting school, she commented:

M: Well, he was always a good student and we treated him just as any other kid. We never tried to make him anything, you know, different than anyone else. We were always open with discussion, explained

> everything. As we said, we explained it to to staff, we explained it to him, everything that was going on. We never, never tried to, you know, hush up what we were talking about. It was just part of our routine, part of life. We accepted it and he had to accept it.

Mr. C.'s warm sense of humor was very evident throughout the interview, and was shared by S. The following exchange concerned an aspect of the relationship between S. and his sister:

> I: It's like it has drawn them closer together.
> M: I would say so. If they didn't fight, they wouldn't be normal in my interpretation. (Laughs)
> F: I know why she complained about him walking so slow, I happened to come along one time with the truck and -
> S: (Laughing) I'd walk and I'd gaze at the birds and -
> F: (Overlapping) They'd be walking to school. He'd be walking along and he'd stop - and then take a few more steps -
> S: Well, I'd often read a book while I walked.
> F: And he'd be gawking some place. (Everybody laughs) I thought it was funny he ever got home.

Punctuation discrepancies were generally absent during the C. family interview, and where such differences were apparent they were quite openly discussed. One such instance involved S.'s perception of his mother as unduly energetic, and Mrs. C.'s perception of her son as unduly lazy. Her approach to encouraging more physical activity consisted of urging him on, but S. often resisted these efforts.

It seemed that this struggle over complementary styles of behaviour created a degree of tension and usually ended with S. maintaining his right to self-definition. Mr. C. shared the perception that S. was sometimes difficult to motivate, but approached his son on a more equal basis. For example, if he was going for a walk, he would invite S. along, and in his view this method of encouraging activity was quite successful.

Both Mr. and Mrs. C. easily adopted complementary and symmetrical positions in relation to S., and for the most part he participated on an equal basis with them. He exhibited a sense of humor like his father's, and was free to razz or to question either parent. When asked to differentiate between his parents, or to describe his relationship to one of them, he usually adopted a more one-down complementary position. The following excerpt is typical:

I: When you made up your mind to go to university, how did your mom and dad react?
S: I don't know. How?
M: Well, I was pleased. I think I always -
F: (Interrupting) I didn't worry too much because you weren't very much help anyway (playfully).
S: Thanks.
M: I would say because I knew in my own mind that he was university material that he could do it if he'd apply himself.
F: Mind you, I don't think there was ever a question of whether he was going to university.

S: Yes. I think I just kind of assumed that
I was going to university no matter that.
F: The only question was, whether he was
going right away or if he should have
stayed out a year.
S: Yes, that -
F: (Interrupting) That was really the only
question.
S: - question, and also what I was going to
take. But I think I always just kind of
assumed that I was going. I didn't
really want to go out and work.

Interactional Patterns Promoting Change

Changes within family C. appear to have occurred very smoothly, so that no sudden or dramatic transformations are readily apparent. Appropriate age-related independence was mutually expected by Mr. and Mrs. C., and S.'s achievement progressed as a matter of course. Throughout the family life cycle, each family member has been encouraged and allowed to pursue independent interests, but such interests were then shared through animated discussion within the family.

As noted by Mrs. C., S. was a good student who thrived on attention, and his academic achievements were well-supported by other family members. Considering the example of physical activity previously discussed, it can be seen that both parents nurtured independent behavior, but approached S. from different perspectives. Whereas Mrs. C. pushed and cajoled very actively, Mr. C. prompted S. by more subtle methods. In effect, this teamwork provided two alternative patterns of encouragement, both of which were potentially powerful as deviation-amplifying feedback.

In some endeavors, internalized feedback guided S.'s behavior. For example, he took full responsibility for his own medications, noting that his stomach informed him if he forgot and thus acted as deviation-counteracting feedback. This basic self-care ability enabled S. to achieve increasing independence, and had allowed him to travel and to live on his own.

Family Rules

On the basis of family interaction patterns promoting stability and change, the following rules can be inferred about the C. family: (a) The parents will share executive authority, together or independently, depending upon the issue, but both will remain open to input from others. (b) Each person will have the right to self-expression and the right to be heard by others. (c) Each person will have the right to question others. (d) The open expression of ideas and emotions will be permitted and encouraged, so that individual growth will be facilitated and the rules can be changed. (e) Each person will have the right to disagree, and to express likes, dislikes, and differences. (f) Each person will have considerable right to comment on others and on their relationships with others, but parents will have more authority in this regard. (g) Each person will have clear responsibilities, but will offer mutual support as required. (h) Humor will be valued as a way of relating. (i) The family will remain open to outside influences. (j) Each person will be encouraged to develop individual potential as much as possible. (k) If anyone feels bad, that person can at least benefit by getting the work done. (l) Whereas father will express a more easygoing, meditative style, mother will express a more worrisome, active style.

CHAPTER V

ANALYSIS, DISCUSSION AND IMPLICATIONS

The purpose of this research has been two-fold: (a) to discover, in the context of cystic fibrosis, patterns of information feedback maintaining the family as a stable unit and promoting family accommodation to individual developmental changes, and (b) to explore the efficacy of the systems interactional framework as an approach to research. In this chapter the four research questions are analyzed and discussed, and the implications for counselling and further research are presented.

Analysis and Discussion of the Research Questions

Research Question 1

What feedback patterns have promoted stability in the family interactional system?

All subject families demonstrated the dynamic stability which is typical of open systems in general. Morphostasis was defined by a range of ongoing interactional behaviors between and among family members. Interactional sequences were characterized by both symmetrical and complementary communicative behaviors, and these alternative patterns appeared to counterbalance each other. For example, Mr. and Mrs. C. often engaged in mildly competitive interactions, defining themselves in a symmetrical manner, but this range of essentially escalating behaviors was then counteracted by the adoption of complementary positions. Thus, deviation-amplifying feedback patterns seemed to promote small escalations, but further change was limited by the introduction of deviation-counteracting feedback.

Stability exhibited by the B. and C. families seemed qualitatively different from that shown by the A. family. In the B. and C. families, punctuation discrepancies were less apparent, communication was more mutually confirming, content and relationship levels of communication were more congruent, and metacommunication was frequently utilized. Stability seemed to be maintained with ease, as each family member readily adopted the various positions inherent to symmetrical and complementary relationships. In contrast, stability of the A. family seemed more precarious and was maintained with greater effort on the part of all family members. A wide variety of idiosyncratic communicative manoeuvres served to minimize and obscure potentially difficult issues, so that an uneasy stability was maintained through considerable ingenuity and effort on the part of family members.

Humor appeared as an important stabilizing factor for all families, but again, was expressed with a slightly different tenor in the A. family. For example, mildly sarcastic humor employed by Mrs. A. in relation to her husband had the effect of counteracting his expression of a more direct comment. The daughter, D., employed humorous remarks in conjunction with more direct comments about her parents, and these seemed to disqualify any criticism she expressed. On some occasions, the laughter shared between Mrs. A. and D. originated in relation to humorous remarks, but on other occasions, their shared laughter seemed to express a mutual understanding about more serious issues. In contrast, all participants in the B. and C. family interviews openly enjoyed humor, and it more often served as an obvious expression of warmth and caring in these families. This finding compares with a similar observation by Anthony (1970), who noted that families in the regenerative phase of coping with illness are characterized by a variety of positive developments, including an increased expression of humor.

Research Question 2

What feedback patterns have promoted change in the family interactional system?

Within all subject families, age-appropriate development of the identified patient had been promoted by deviation-amplifying feedback. In the B. and C. families, parents were generally united in their support relative to the identified patient, and control was not an issue. All family members were thus able to share and enjoy the satisfaction of mastery and achievement. In the A. family, parents were united in a protective pattern relative to the identified patient, and control had become an issue. The members of this family were less able to share and enjoy the satisfaction of mastery and achievement, and the daughter showed an increased reliance upon extra-familial sources of support.

At various times, each of the three identified patients showed the ability to resist a parent who attempted to define the parent-child relationship from a complementary, one-up stance. For example, when Mrs. B. tried to tell her son, J., about the best study methods for university, he persistently resisted any response from the complementary one-down position, maintaining instead that he already knew how to manage his course work.

Two findings with regard to change were of particular interest: first, that the B. family had altered family interaction patterns subsequent to the death of a daughter, and second, that the protective pattern of the A. family, contrary to expectation, had promoted independent adaptation. With respect to the first finding, death is usually conceived of as a very negative event for any family, and there is no doubt that the earlier death of the B. family daughter presented an extremely painful and difficult experience. However, it also triggered the chain of events which led to a richer, more family-oriented lifestyle. In contrast, the earlier experience of a death in the A. family, which was undoubtedly a similar experience of pain and distress, had not intensified the family's quality of life and had failed to stimulate obvious changes in family interaction patterns. These family environments seem to have provided their members with very different resource systems from which to accommodate drastic family change. Whereas one system was open to metacommunication, and was able to resolve the grieving process, the other system did not allow metacommunication and the grieving process seemed to remain unfinished.

With respect to the second finding, the success of the parental protective pattern revealed in the A. family was of interest because protective patterns are usually associated with relatively dysfunctional adaptation on the part of the identified patient. However, the influence of the A. family protective pattern obviously differed from the influence of the classic overprotective mother/withdrawn father constellation. An important discriminating factor appeared to be that the A. family protective stance was occupied by both parents, who supported each other in implementing joint protective efforts. While the daughter may have enjoyed a closer emotional relationship with her mother than her father, she was not troubled by the conflicting expectations one would probably discover in the classic overprotective mother/withdrawn father family system.

Just as with family stability, the qualitative character of morphogenesis shown by the A., B., and C. families seemed to vary. Currently, changes in the B. and C. families occurred rather smoothly, so that drastic behaviors were not necessary to effect change, and everyday developments were easily accepted. At one time, changes within the B. family had not been so readily facilitated, but as previously noted, the death of a child had triggered a gradual process of growth, so that the family environment was now more sensitive to ongoing self-expression and development. In the A. family, certain changes accomplished by the daughter had not been readily accepted by the parents, and the process of change seemed more troubled and difficult.

Research Question 3

On the basis of feedback patterns, what rules can be inferred about the family interactional system?

As rule-governed systems, the three families showed a number of similarities and differences. While the A. and C. families had apparently operated according to consistent rules through several phases of the family life cycle, the B. family had undergone a major rule change subsequent to their first daughter's death. While their original rules had inhibited metacommunication, emphasized the primacy of work, and maintained a more rigidly complementary relationship between Mr. and Mrs. B., the new rules were much more facilitative of ongoing development and self-differentiation. Currently, the B. family resembled the C. family in this respect. Family rules generally allowed flexibility, promoted metacommunication, encouraged self-expression, and valued humor. As well, the hierarchy of authority in each family clearly descended from the parental subsystem. In their orientation toward growth and development, B. and C. family rules seemed to be efficient and clearly-defined. By way of contrast, rules governing the A. family appeared more complicated and vaguely-defined. Overall, the maintenance of family stability emerged as the primary emphasis. Open metacommunication was prohibited, less flexibility was allowed in the parental subsystem, and lines of authority were not clearly delineated. The writer speculated that the earlier experience of death in the A. family, occurring in the context of these rules, merely acted to reinforce the maintenance of the same interactional patterns.

Research Question 4

What are the limitations and advantages of the interactional perspective as a system of research?

While the system of research explored throughout this study revealed several commendable strengths, the approach also suffered from a number of limitations. Perhaps the major limitation derived from the dependence of data collection and analysis upon the interviewer's skill and experience. Although the interviewer possessed a counselling background of several years duration, his exposure to family interviewing was very limited, and he claimed little previous experience with the method of pattern recognition and analysis. This inexperience factor affected the research process at several junctions, as follows:

1. In the development of the interview schedule, the writer persistently encountered his own orientation toward the content level of communication. For instance, the interview schedule was constructed to elicit pictures of interactional sequences which had occurred at different stages in the family life cycle. Certainly the interview was somewhat successful in obtaining this data, but as the research proceeded, the writer increasingly recognized that the way in which an individual participated in the family interview typically provided clearer relational information than the content of each participant's response. The use of videotaping instead of audiotaping would have been helpful in this respect.

2. A related difficulty derived from the writer's 29 years of experience with the English language. As a symbolic system, English is a static and lineal tool which guides one's perceptions and thinking in misleading ways when applied to the understanding of complex systems. For example, the writer learned it was easier

to assert that a person is overprotective, thereby affixing a static and negative label, than it is to state that one person shows overprotective concern which elicits dependent behavior from a second person through the process of a reciprocal relationship. Such limitations of language presented an ongoing challenge to the investigator's ability to punctuate events in the recursive manner appropriate to the study of complex systems.

3. The writer's personal resistance to family interviewing was considerable, and the prospect was rendered less threatening by arbitrarily limiting participation to the identified patient and both parents. While the complexity of interviewing was lessened by thus excluding siblings and other significant persons, the value of information obtained about these significant individuals was likewise diminished. Again, asking about interactional sequences was less effective than having individuals represent themselves, and this finding underscored the importance of including all family members in this type of interview.

4. The preparation of a detailed, semi-structured interview schedule also served to lessen the interviewer's anxiety about family interviewing. Through the process of constructing and administering this

interview schedule, the writer learned about a new way of interviewing, but during the actual interview the schedule sometimes proved a hindrance. Each family exhibited a frustrating tendency to deviate from the interview format, and the writer learned it was more effective to explore whatever material the family presented by applying the general interview style and format with some flexibility. The complexity of the interview schedule combined with the complexity of family response frequently overtaxed the interviewer's concentration, so that significant messages were not pursued effectively. The interviewer had not yet attained the desired state of observant inattention, and could thus be likened to the character in the following poem from Watts (1957):

> The centipede was happy, quite,
> Until a toad in fun
> Said, "Pray, which leg goes after which?"
> This worked his mind to such a pitch,
> He lay distracted in a ditch,
> Considering how to run. (p.27)

5. Since the writer's understanding of the significance of differences evolved throughout the research process, the delination of differences was often inefficiently pursued during family interviews. The interview schedule emphasized differences before and after certain events, and in retrospect it appeared that differences (and the lack thereof), between and

among family members, were perhaps of greater significance in defining feedback patterns. For example, with respect to the A. family, a more direct examination of differences and similarities between Mr. and Mrs. A. would likely have clarified the complementary aspects of their relationship.

Other major limitations of the research system derived from the high probability of obtaining both socially desirable response sets and experimenter bias. Since these difficulties were expected beforehand, it was possible to obviate the effects to some extent by regulating both the manner of interviewing and the approach to analysis. The triadic interviewing method emphasized the value of eliciting each person's perceptions, and thereby increased the likelihood of discovering discrepancies between and among family members. As well, the interview situation was explained in a positive way, so as to elicit family cooperation in teaching the interviewer about their particular situation. While on the one hand questions were usually very specific and directive, on the other, they were open to participant interpretation. For example, typical questions were the following:

> What differences were there for his routine
> after that time as compared to before?
> How has having cystic fibrosis been significant in your life?

What was your reaction to that particular
change?

Throughout the analysis, the credibility of informants was judged by examining verbal and non-verbal congruency, and by checking the descriptive pictures provided by one informant against those provided by others. Further corroboration was obtained by comparing descriptive pictures of interactional sequences to the actual sequences of interaction demonstrated throughout the interview. As Becker (1958) notes, confidence in the reliability of conclusions about data varies according to evidence received from different perspectives and in different forms.

While conducting this research, the writer frequently encountered the attitude that with a sample size of only three families nothing could be concluded. The writer took exception to this position, first, because it was a mistake to presume that science proves anything conclusively, and second, because certain findings of the study were explicitly tentative in nature and were limited specifically to the family system about which they pertained. The scientific process involves the periodic testing of hypotheses against available evidence, and such hypotheses are subsequently modified to account for data in more powerful ways. For the purposes of studying complex human systems, the intensive single case design is particularly applicable. It is safest to assume that information is processed according to idiosyncratic meanings in each system, so that the individual system provides its own best explanation. Moreover, this general approach to research, wherein each observation or intervention of the participant observer serves to modify hypotheses and to guide further participation in the system, provides the practitioner with a useful bridge between experimental and applied psychology.

Thus, the method of pattern recognition and analysis associated with the systems interactional framework can be generalized to a wide variety of interactional situations. In many research contexts, the sheer number of potentially significant variables complicates any realistic attempt to establish control. Since the interactional approach to research remains essentially open to discovery, it is eminently suited to revealing the more influential variables operating within a system.

As noted in the second chapter, the systems interactional perspective represents a shift away from the lineal conception of reality, where changes are effected by physical energy, to a more complex, recursive conception, where changes are effected by information flow. Differences are significant not only because they enable the investigator to translate external reality into abstract representation, but also because they are the basic unit of information flow in the communicative process. As system behavior is regulated by information feedback, sequences of interaction tend to be repeated in regular, patterned ways so that pattern recognition and analysis become the primary means of studying system operation. According to Judson (1980), this modus operandi has long been applied to such diverse disciplines as geology, mathematics, medicine and astronomy. However, formal applications to the understanding of complex human systems have just begun.

In addition to the advantages already discussed, the system of research applied in this study exhibited tremendous value as a personal learning experience for the investigator. The writer was introduced to a new way of looking at problems, and to a new style of interviewing. The experience which was acquired will have immense carryover value to counselling practice. As well, it was discovered that the system of research was exciting to work within. It allowed the writer to remain open to the unexpected and to the idiosyncratic, as exemplified by the repercussions of death found in the B. family. Finally, through facilitating openness to such discoveries, the research system assisted in the generation of hypotheses to guide further research and counselling practice.

Implications for Counselling

The systems approach to family counselling explicitly recognizes that the way in which any problem is initially conceptualized will influence subsequent counselling interventions (Tomm, 1980). To the majority of family therapists, assessment is an ongoing process of hypothesis testing whereby the patterns of family response which are observed in relation to various therapeutic manoeuvres serve to guide following interventions. By examining behaviors in terms of the complex feedback patterns which maintain and modify them, a great advantage of the systems framework is realized: change can be affected by counsellor intervention into the system at any number of points.

Tomm (1980) identifies the two most prominent approaches to family therapy as the structural school, exemplified by Minuchin (1974), and the strategic school, exemplified by the Milanese group of Palazzoli et al. (1978a). Structural therapists work from the assessment of subsystems and subsystem boundaries, effecting change through restructuring manoeuvres which include manipulating space, joining operations, confronting, and marking boundaries (Minuchin, 1974). The structural approach was illustrated in the earlier discussion of therapy with the families of intractable asthmatics, as implemented by Liebman, Minuchin and Baker (1974). The strategic approach to family therapy effects change at the level of family rules, and emphasizes the use of positive connotation, whereby the therapist confirms the behavior of all members of the system for its contribution to overall family stability and cohesion. Positive connotation sets the stage for the prescription of a complicated counterparadoxical directive aimed at changing basic system rules (Palazzoli at al., 1978a).

Both the structural and strategic approaches to family therapy show a concern with altering dysfunctional family rules. Often, simply bringing all family members together and insisting that each be given the right to verbalize his or her own opinion represents a significant alteration of the rules. Haley (1976) notes that therapy usually involves negotiating small agreements about specific, concrete issues, with the expectation that these changes will generalize to other areas. He cautions against minimizing the importance of seemingly small problems presented by a family, since such problems may be analogous to more serious problem areas.

The present research implied several counselling interventions which might be implemented to promote more functional individual and family adaptation in the context of cystic fibrosis. On a preventative basis, it is suggested that the style with which medical care is delivered represents a metaphor of the ideal family approach to the chronic illness situation. Since total family involvement, with particular emphasis upon mutual and flexible sharing within the parental subsystem, emerged as a desirable goal, it appears crucial that clinic care be organized around the notion of the family as patient. While conducting this research, the writer discovered considerable resistance to the practice of family interviewing among health care professionals, an observation perhaps indicative of an important but largely unfulfilled need of professional training.

Just as including the entire family in the health care process might obviate adaptational difficulties in the earlier years, so might a slightly different approach during the teenage years serve to ease the transition into responsible adulthood. It is suggested that emphasis upon obtaining occasional care as a separate patient, apart from the parents, might be initiated during these years to serve as a metaphor of appropriate family disengagement and individual self-differentiation.

More specific counselling interventions can be illustrated by considering situations likely to present problems. The example of an adolescent patient caught in rebellion against parental and medical control is encountered with some frequency in clinic settings. In this type of difficulty, which occurs as a transitional problem associated with the specific family life phase, parental and medical restrictions operate within a circle of feedback which includes the adolescent's rebellious behavior. Both restrictive and rebellious behaviors escalate one another, and if the interactional system operates according to rules which prevent metacommunication, the problem cycle is likely to persist. Parents eventually perceive their adolescent as irresponsible, while the adolescent in turn views the parents as overly restrictive. All participants in the interaction feel frustrated, angry and unloved. This impasse can be approached with several interventions, such as the following: (a) The family rule which inhibits metacommunication is violated by meeting in a group where talking and listening are facilitated. (b) Parental control is connoted positively as caring behavior. (c) Adolescent rebellious behavior is connoted positively as indicative of the strength and determination to attain independence. (d) Small changes are negotiated to disengage parents from areas of self-care responsibility that rightfully belong to the adolescent.

Identical methods of positive connotation might also be used in the overprotective mother/withdrawn father situation, with additional interventions devised to (a) increase mutual parental involvement in spouse-related activities, (b) increase joint mother-father involvement in parenting activities, and (c) increase father involvement in activities with the identified patient. As an example of the latter intervention, a father and his son might be directed to spend one evening a week sharing some common interest outside the house. Assuming that the mother controls rule-making in the family, the father and son might also be directed to allow her to set the rules in relation to certain family issues. If this paradoxical directive is resisted, the father and son violate a major rule themselves. If the task is accepted, the mother is likely to deny her rule-making authority, and thus initiate an exchange leading to open conflict and negotiation. Interventions such as these characterize the ongoing counselling process.

Implications for Further Research

The system of research which was applied in the present study could be used to advantage throughout the counselling field. With respect to the problems of adaptation in the context of cystic fibrosis, a number of interesting questions have been raised. A longitudinal study conducted in a clinic setting as an integral aspect of the treatment program would allow simultaneous exploration of several issues, including the following:

1. The findings of the present study indicated that a strong parental coalition relative to issues of age-appropriate independence is associated with relatively successful adaptation on the part of teenage and young adult cystic fibrosis patients. In addition, qualitative aspects of family life differed according to the members' flexibility of involvement and their capacity to metacommunicate. Further research is indicated to confirm these findings across all age groups.

2. Presumably, the process exhibited by the overprotective mother/withdrawn-father type of family differs from the process of family organizations revealed in the present research. Although this classic dysfunctional family pattern is often mentioned, it remains poorly understood. This state of understanding probably derives from the manner in which the pattern has been formulated: negative, lineal characteristics have been inferred, and these have in turn implied that mad or bad parental behavior is solely responsible for problems encountered by the identified patient. Additional research is suggested to discover the morphostatic process of such family systems, and to explore the efficacy of systemic counselling interventions in the promotion of functional family adaptation.

3. A study of bereavement among cystic fibrosis families (Kerner et al., 1979) did not provide data relating interactional patterns to the bereavement process, although it was suggested that all families demonstrated reasonably open communication. Further research is indicated to examine differences in interactional patterns before and after the event of death. It is expected that bereavement is more readily facilitated in those families showing

capacities for metacommunication and flexible, mutual involvement.

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APPENDIX A

THE CHRONIC ILLNESS CONTEXT: CYSTIC FIBROSIS

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Cystic fibrosis was initially recognized by a Swiss physician, Guido Fanconi, in 1936, and has since been described as a "generalized disorder that affects the exocrine glands of the body, causing them to secrete abnormally thick, viscous mucus" (Marcotte, 1975, p.33). Every organ system of the body is affected in some fashion during the course of the disease, but progressive pulmonary deterioration is associated with over 95% of the morbidity and mortality (Wood, 1979). Cystic fibrosis is a hereditary condition occurring with an incidence of approximately 1:2000 live births in a white population (much less frequently in non-white populations), and appears to be transmitted as an autosomal recessive trait, independent of sex linkage, found in approximately 1 in every 20 white individuals (Wood, Boat & Doershuk, 1976; Wood, 1979).

Diagnosis is typically made at birth or in the early years on the basis of various clinical symptoms or a family history, and is confirmed by the finding of elevated sweat electrolyte levels upon administration of a sweat test. Ideally, a comprehensive treatment program, emphasizing family and patient responsibility, and the development of a positive but realistic outlook is then implemented under the ongoing supervision of an outpatient clinic physician. A description of the treatment program as advocated by Wood (1979) will provide the reader with a clearer picture of the implications of this condition.

Aside from the overall importance of a positive treatment philosophy, attention must be given to reversing or slowing progressive pulmonary deterioration. The patient is encouraged to cough at every opportunity as this action clears mucus from the upper airways. Chest percussion and drainage, procedures which are time-consuming, uncomfortable, and often require the assistance of a second person, are usually performed one to four times daily in order to move mucus into the upper airways and subsequently out of the body. Patients may also receive intermittent aerosol therapy through a mask or mist tent as a means of delivering drugs in a mist suspension to assist in the loosening of tracheobronchial mucosa. In some patients, physical activities which facilitate deep breathing and coughing are encouraged. All cystic fibrosis patients receive intermittent antimicrobial therapy, often by means of an elective two-week hospital admission informally called a "clean-out", during which antibiotic therapy is combined with intensive aerosal therapy and chest physiotherapy.

Almost all patients require some form of gastrointestinal therapy to assist in digestion and absorption. Difficulties with these two basic body processes lead the cystic fibrotic individual to have an enormous appetite, and diet must be high calorie/ high protein, supplemented with certain vitamins and possibly with a variety of other nutritional additives. As well, pancreatic enzymes are typically taken in pill form prior to every meal. Salt intake must be increased, particularly in hot weather, to counter the possibility of heat prostration. Overall, the gastrointestinal effects of cystic fibrosis are associated most commonly with an enormous appetite, small stature, and frequent, foul-smelling bowel movements.

A wide variety of serious complications can arise during the progression of the disease, and all of these require specialized medical treatment. These complications include congestive heart failure, pneumothorax, hemoptysis, mucoid impaction of the bronchi, intestinal obstruction, glucose intolerance which resembles adult-onset diabetes, and respiratory failure. The latter complication usually occurs in the terminal stage of cystic fibrosis, and as Wood notes, the "single most important prognostic factor for patients in respiratory failure is the patient's will to live" (p.195).

Psychosocial therapy is important throughout the patient's life cycle, from the beginning, when the family will need assistance in coming to terms with the diagnosis and its implications, through the uncertainties and frequent rebelliousness of adolescence, and into the intensified decision-making of young adulthood. It is vital that the patient have a supportive, trusted confidant, who is knowledgeable of the disease and can assist in decision-making while promoting a positive, independent lifestyle and attitude. The genetic aspect of the condition places an emotional burden upon the family, and the inevitably fatal outcome casts a long shadow over matters such as education, career, peer relationships, marriage and reproduction. Emotional adjustment for the male cystic fibrosis patient is complicated by the fact of a greater than 97% chance of infertility; female patients, while fertile, must cope with increased pregnancy risks and a shortened span of years as capable mothers.

All patients with the condition face a high degree of uncertainty regarding its progression for themselves as individuals. Although the terminal stage is typically death by way of pulmonary involvement, the stages preceding death are highly variable and not readily predictable. Some patients deteriorate gradually over the years, others deteriorate suddenly and die within two to five years, and still others deteriorate in the beginning but later experience lengthy periods without much change. From a historical perspective, prognosis has changed dramatically, and this can likely be attributed to factors such as earlier diagnosis and treatment, more effective treatment, and more aggressive overall medical management. Rosenlund and Lustig (1973) reported that in the early 1950's most individuals born with cystic fibrosis died within the first year, and that in the early 1960's only a few lived beyond the age of 10 years. More recent data from the United States (Wood, 1979) suggests that about 16% of known patients are 18 years of age or older and that the median life expectancy for all patients is now greater than 19 years.

APPENDIX B

INTERVIEW SCHEDULE

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Basic Information (from all participants)

Establish names and ages.
Establish living circumstances.
Identify other family members and their living circumstances.
Work: What kind? Where? Amount of time? What other work or school are you involved in?
Leisure activities: What? With whom? How often?

Information about Cystic Fibrosis in the Family (primarily from identified patient)

Is there anyone else in the family who has cystic fibrosis? Who?
How has having cystic fibrosis been significant in your life?
What people, outside of your family, have been significant in your life?
What age were you when cystic fibrosis was diagnosed?

Time of Diagnosis (primarily from parents about each other)

What reactions did (he, she) have when cystic fibrosis was diagnosed?
What particular ways did (he, she) have of showing that?
What changes were there in (his, her) routine?
What reaction did (he, she) have to these changes?
What was your reaction to that?
What changes were there in the activities you did together?
What reactions did the other children have?
Were there any other significant changes at that time?
What reactions were there?

Time of Entering School (from all participants)

What changes were there in (his, her) routine?
How did (he, she) react to these changes?
How did (he, she) indicate to you that this was (his, her) reaction?

What changes were there in treatment routine?
Reactions to these changes?
What reactions did (he, she) have to starting school?
How did (he, she) indicate this was (his, her) reaction?
What other significant changes were there in the family around the time of starting school?
What reactions did (siblings) have to all these changes?

Time of Adolescence

(from all participants)

What changes were there in treatment routine at this time?
How did (he, she) react to these changes?
What reactions did (siblings) have to these changes?
In what particular ways were these reactions shown?

(from identified patient)

How is the treatment routine managed now?
How is treatment routine handled differently on holidays or when parents are away?

(from all participants)

What changes were there in activities that the identified patient became involved in?
What reactions were there to these changes?
How were these reactions shown?
Were there any other significant changes at this time? Reactions?

Work and Career Plans

(from identified patient)

What particular plans do you have about work and pursuing a career?
Who in particular have you discussed these plans with?

(from all participants)

What reactions did (he, she) have to these plans?

What particular way did (he, she) have of indicating that?
What was your reaction to that?
How did (siblings) react to these plans?

Closing (from all participants)

Is there anything significant that we haven't talked about, that you would like to add?

APPENDIX C

CONSENT TO PARTICIPATE

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in a research study concerned with
family accommodation and change in a situation
involving cystic fibrosis

Having had the above study described to us by Graeme Clark, we agree to be interviewed as a family and to provide information about the ways in which we have managed various family tasks and issues connected with the condition of cystic fibrosis. In exchange, we understand that we will receive feedback about the results of the study, after it is completed.

Further, we understand that the interview (of about 60 minutes duration) will be recorded on audiotape and that the tape will be erased following completion of the study. We understand that we will not be identified by name and that specific information which could be used for identification will not be included in the research report. It is also understood that no persons other than those directly involved in the study will have access to confidential information.

Signed: ______________________

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Witnessed: ______________________

Dated: ______________________